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TREATMENT DECISIONS AT THE BEGINNING OF LIFE: LEGAL, MEDICAL AND MORAL ASPECTS

by

PATRICIA LEONE JAMES

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **TREATMENT DECISIONS AT THE BEGINNING OF LIFE: LEGAL, MEDICAL AND MORAL ASPECTS**, submitted by Patricia Leone James in partial fulfillment of the requirements for the degree of LL.M.

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ABSTRACT

This paper examines the issues arising upon the birth of seriously ill and defective infants which are subject to varying interpretations depending on whether the analysis is from a medical, moral, legal or policy perspective.

From a medical perspective, the critical problem is that prognosis is extremely difficult to assess. Thus, medical decisions are made amid conditions of great uncertainty. The extreme variety and complexity of the cases as well as the wide variety of constantly changing therapies result in widespread disagreement among medical commentators as to the criteria or conditions which justify a decision to withhold or withdraw treatment. There is also disagreement as to whether parents or physicians should bear primary responsibility for making these decisions.

Legal analysis has focused on two issues: (1) Who has the right to make such decisions? and (2) What criteria may lawfully be considered in making such a decision. Parents are generally permitted to make medical decisions for their children provided their decisions are in accordance with their child's best interests. The convenience and interests of others may not override the child's right to medical treatment. Other legal issues addressed concern the issue of "consent" under the Canadian Criminal Code and the effect of the Canadian Charter of Rights and Freedoms on the provision and withdrawal of medical care.

Ethical and moral theories regarding the selective nontreatment of ill and defective infants are analyzed and range from extreme sanctity of life positions to quality of life and personhood theories which would deny treatment or permit the selective killing of infants who do not meet stated criteria.

It is suggested that neonatal decisionmaking would be enhanced by the development of substantive guidelines and criteria specifying the conditions in which treatment could be withdrawn. For uncertain cases the decisionmaker would have to assess the probable harms and benefits of proposed therapies and then exercise his/her discretion in making the decision. As an added protection in such cases, a mechanism for reviewing these decisions should be adopted. Various alternatives are analyzed and a recommendation is made as to the most appropriate forum for such review.

TABLE OF CONTENTS

VOLUME I

Chapter One: Medical Issues in Neonatal Practice Today

Page

I. Introduction 1

II. Development of Neonatology 7

A. History 7

B. Patient Characteristics 11

C. Economic Considerations 13

III. Medical Practice 17

A. Development of Neonatal Units in Canada . 17

B. The Role of Neonatologists and Other Team Members 19

1. The Neonatologist 19
2. The Nurses 21
3. Medical Consultants and Support Personnel 22

C. Current Medical Practice 23

1. Introduction 23

(a) Crane Survey 26
(b) Magnet and Kluge's Study 30

2. Issues in Neonatal Medicine 33

(a) Passive Euthanasia 33
(b) Active Euthanasia 34

Page

(c) Admission to Units 43
(d) Communication with Parents . . . 45
(e) Who Makes the Decision?. 49
(f) Decisionmaking Procedure 53
(g) Criteria for Decisionmaking . . 54

(i) Medical Criteria 54
(ii) Non-Medical Criteria . . . 58

(h) Management of Infants Selected for Non-Treatment 60

3. Treatment Debates in the Medical Literature 61

(a) Down's Syndrome 61
(b) Spina Bifida 62
(c) The Medical Debate Over the Treatment of Spina Bifida . . 66

1. John Lorber 70
2. John Freeman 78
3. Robert Zachary 81
4. Richard Gross 86

(d) Conclusion 88

Chapter Two: The Law

I. Introduction 110

II. Consent to Treatment 111

A. Requirements for a Valid Consent 111

B. Consent and the Criminal Law 125

C. Consent to the Medical Treatment of Infants 135

1. Parental Consent Required 135
2. When Parental Consent is not Required 137

        3. Parental Refusal of Consent 143
            (a) Child Welfare Authorities . . . 146
            (b) The Courts Parens Patriae Jurisdiction 157
    D. Criteria Governing Treatment Decisions . 166
        1. Doctors 166
        2. Parents 168
        3. Courts and Child Welfare Agencies . . 168

III. Administering Treatment 173
    A. Physicians' Duties 173
        1. Duty to Refer (Consult) 174
        2. Duty to Treat 178
    B. Liability for Breach of a Physician's Duties 180

IV. Withdrawing Treatment - Passive Euthanasia . . 184
    A. Patients Right to Refuse Medical Treatment 184
    B. The U.S. Experience 184
        1. The Permanently Comatose Patient . . 185
        2. Poor Quality of Life 191
            (a) Terminal Illness 191
            (b) The Seriously Ill Infant Who is Neither Comatose nor Terminally Ill 203
        3. Uncertain Cases 220
        4. Procedural Issues 225
            (a) The Delegation Approach 226
            (b) The Non-Delegation Approach . . 229
    C. Anglo-Canadian Jurisprudence 237

Page

1. The British Position 237
2. Canadian Law 242
    (a) Criminal Code Provisions 242
    (b) Child Welfare Legislation . . . 256
    (c) Caselaw 256
    (d) Constitutional Law 267

V. Active Euthanasia 280

VI. Conclusion 282

VOLUME II

Chapter Three: Moral Aspects of Neonatal Decisionmaking 318

I. Two Major Ethical Theories 318

II. Deontological Theories 323

A. Sanctity of Life Doctrine 323
1. Judeo-Christian Tradition 324
    (a) Immanuel Jakobovits 324
    (b) Paul Ramsey 326
2. Secular Tradition 329
    (a) Richard Sherlock 329
3. The Extraordinary Means Principle as a Limiting Factor in the Sanctity of Life Tradition 333

Page

B. A Pluralistic Deontological Theory 343

III. Consequentialist Theories 352
  A. Richard McCormick 353
  B. Joseph Fletcher 356
  C. Richard Brandt 359

IV. Personhood Theories 361
  A. Michael Tooley 362
  B. Peter Singer 365

V. Withholding Treatment in the Child's Best Interest 371
  A. Robert Weir 371
  B. Tristram Engelhardt 377

VI. Procedural Approaches 380

VII. The Euthanasia Debate 386
  A. Killing and Allowing to Die - Is There a Difference? 388
  B. The Debate Between Williams and Kamisar . 401
    1. Williams Proposal 401
    2. Kamisar's Rebuttal 403
    3. Critiques of Kamisar's Wedge Argument 404

Chapter Four: Criteria Guiding Decisionmakers . . 423

Page

I. Introduction 423

II. The Factual Basis of Decisionmaking 427

- A. Accurate Diagnosis 428
- B. Prognostic Uncertainty 429

III. Determining the Infant's Best Interests . . . 434

- A. Ethical Guidelines 434
  - 1. Harms and Benefits in the Neonatal Context 437
  - 2. Whose View Shall Govern? 442
    - (a) Best Interests Standard 443
    - (b) Substituted Judgment Test . . . 444
- B. Application of Ethical Guidelines 448
  - 1. Selection by Categories 448
  - 2. Decisionmaking in Borderline Cases . 461
    - (a) The Distinction Between "Ordinary" and "Extraordinary" Treatment 461
    - (b) Bayes Theorem 465
    - (c) Suggested Approach for Difficult Cases 469

Chapter Five: Procedural Issues 477

I. Introduction 477

II. Who Should Decide? 478

- A. Parents 480
- B. Physicians 485

Page

C. Ethics Committees 489

D. The Courts 491

E. Conclusion 494

III. Reviewing the Decisionmaking Process 496

A. Legislative Review 496

1. The Canadian Experience 496
2. The United States Experience 497

(a) The Baby Doe Case 498
(b) The Federal Government's Response 499

(i) Initial Response 499
(ii) The Revised Rules 503
(iii) The Final Rules 508
(iv) The Child Abuse Amendments 511

(c) Comments Regarding Legislative and Administrative Control Over Selective Nontreatment Decisions 514

B. Judicial Review 521

1. Arguments in Favour of Judicial Review 521
2. Arguments Against Judicial Review . . 525
3. Response to Arguments Against Judicial Review 529

(a) Courts are Too Slow Argument . . 529
(b) Frohock's - Incrementalist versus Final Decisionmaking . 529
(c) Dr. Havard's - Adversarial versus Cooperative Approach . 530

C. Internal Administrative Review 531

Page

D. Hospital Ethics Committees 538

VI. Conclusion 547

Bibliography 569

Newspaper and Periodical Articles 593

Table of Cases 595

Chapter 1: Medical Issues in Neonatal Practice Today

I. Introduction

Advances in modern medical technology have made it possible to save the lives of many newborn infants who would have died at birth or soon after a decade ago. These advances which include new drug therapies, intensive care regimens, surgical and resuscitative techniques, and the use of highly sophisticated equipment have resulted in the correction of many severe handicaps and minimized the effects of others. [1] The majority of the infants treated in neonatal intensive care units will go on to lead normal and productive lives.

However, these new technological advances have proven to be a mixed blessing. A growing number of children have been salvaged who suffer from devastating physical or neurological deficits, or both. These may arise from the infant's condition or they may occur as a result of the treatment itself. [2]

The central difficulty in neonatal medicine is that prognosis is "extraordinarily difficult". [3] A forecast can be made as to a child's future quality of life for certain congenital abnormalities and conditions. But for the dominant problem in neonatology - the premature infant - long term prognosis is extremely difficult to assess, since often the results of treatment will not be known for years.[4] For example, a premature infant may be placed on a respirator at birth. Within a day or so, a diagnostic test may reveal the infant has suffered a severe intraventricular-brain hemorrhage. The infant could end up being severely impaired, moderately impaired or completely normal.[5]

Prognosis in neonatal care is also difficult to assess since so many factors can affect the outcome of treatment. Each year there are new advances made in neonatal practice and the asessments of treatments as little as five years ago often cannot be applied to current treatment situations. New therapies keep altering both the probabilities and the possibilities.[6]

Thus, neonatal staff must often decide amid conditions of great uncertainty whether to treat an infant at all, and once treatment has begun, whether to withdraw all or certain therapies if treatment has not succeeded. These decisions must be made, while keeping in mind that "overtreatment may be as harmful and may violate the infant's interests as much as undertreatment."[7]

The issue of overtreatment is as important as that of selective non-treatment since, as one medical commentator points out, "today's doctors probably order excessive treatment far more commonly than they practice non-treatment." [8] Joel Frader, a tertiary care pediatrician at the Children's Hospital of Pittsburgh, explains why this occurs: [9]

> Overtreatment abounds because physicians receive little moral training and reap few rewards for moral courage. Overtreatment persists because of the false belief that technology can solve all our problems, if only pushed long and hard enough. And excessive treatment continues because, realistically or not, the medical world fears ... criminal prosecution and malpractice claims ...

Despite this practice, the debate in neonatal medicine has thus far focused on the ethics of foregoing life-sustaining treatment from selected newborns. This issue was initially brought to public attention with the publication of two articles in the October 25, 1973 issue of the New England Journal of Medicine. In the first article which was entitled, "Moral and Ethical Dilemmas in the Special-Care Nursery", the authors, Raymond S. Duff, a professor of pediatrics in the Yale University School of Medicine, and his associate, A.G.M. Cambell, described their policy of selective non-treatment of infants in the

Yale-New Haven Hospital. [10] They revealed that it was their practice, with the concurrence of the parents, to withdraw treatment where the prognosis, even with optimal treatment, was judged to be dismal or hopeless. The authors made a plea for allowing the parents a choice under these circumstances and hoped that their article would break "the public and professional silence on a major social taboo ...". [11]

The author of the second article, Dr. Anthony Shaw, described several cases in which a decision to withdraw treatment was considered. He argued that parents could make informed decisions if they were afforded access to a range of resources and afforded sufficient time for contemplation of the alternatives. [12]

Following the publication of these articles there has been a continuing debate amongst physicians, lawyers, philosophers and ethicists regarding the ethics and legality of withholding medical treatment from certain infants. [13] While there is intense disagreement among individuals within the same disciplines, each discipline tends to examine the issue from a particular perspective and bias which must be recognized. Lawyers have tended to focus on the developmnent of "formal procedures" to guarantee the consideration of all relevant factors to assure just and fairly reached decisions. Medical writers have tended to focus on the technical criteria for decisionmaking and medical uncertainty regarding prognosis, while ethicists and philosophers have generally considered the moral status of handicapped infants, and have attempted to establish ethical guidelines to govern decisionmaking. [14]

The debate surrounding the care of defective infants involves substantive as well as procedural issues. The major substantive question is of course, whether there is a particular group of infants from whom we may morally and legally withhold treatment.

If the answer is yes, a number of other substantive issues must be resolved. What criteria should be used in deciding which infants should not receive care? Should the decision be based solely on the "best interests" of the infant or should the wishes and abilities of the parents and/or society be considered? What weights should be ascribed to these various interests? Should parents be allowed to withhold treatment that will result in death for their infant if someone else is ready and willing to care for the child?

For those infants who are selected for non-treatment, what treatment can be withdrawn? Is there a relevant moral difference between killing and letting die? If there is no relevant moral difference, should the law differentiate between active and passive euthanasia?

The procedural issues involve two questions. The first is, who should decide?, while the second is, what decision-making procedures should govern the decision-making process to ensure that the substantive criteria are fairly applied?

This paper will examine these issues from a medical, moral and legal perspective:

The first chapter will focus on the medical issues - current medical practices and debates within the medical literature regarding the practice of selective non-treatment.

The second chapter will review the current law (substantive and procedural) in relation to the treatment/nontreatment of defective infants.

The third chapter will consider what the law should be. The views of various philosophers and ethicists about the morality of selecting certain infants for non-treatment, the criteria that may be ethically considered and the moral distinction (if any) between killing and letting die will be presented and evaluated.

The fourth chapter will discuss the development of guidelines and criteria in neonatal decisionmaking, while the fifth chapter will determine who should make these decisions and examine possible procedures for reviewing such decisions.

II. The Development of Neonatalogy

A. History

Neonatology is a major subspecialty of pediatrics concerned with the study, care and treatment of the newborn during the first 28 days of life. Prior to 1960 the discipline did not exist, but it has become one of the fastest growing subspecialties of pediatrics in the 1980's.[15]

Historically, there was little medical interest in newborns (neonates) since there was little medicine could do to enhance seriously ill and premature infants' chances of survival. Initial medical interest in these infants began with the discovery that small and premature infants who were able to maintain a normal body temperature had an increased chance of survival. This discovery led to the development of the incubator and marked the beginning of modern newborn medicine. [16]

During the 1920's, the first premature nurseries were opened. At that time care for the infants focused on keeping them warm, adequately nourished and protecting them from serious infections. [17] In the 1930's and 40's, oxygen began to be administered to assist infants with respiratory difficulties. Yet during this period and throughout the 1950's, there was no aggressive treatment given beyond incubation and the administration of oxygen. 18

A transformation in medical attitudes towards the care and treatment of the newborn occurred in the 1960's as a result of the development of intensive care units in adult medicine. The success of these units, coupled with new technological advances and a growing knowledge of newborn physiology, led to the development of neonatal intensive care units (NICU's) and the implementation of aggressive treatments for newborns as well. [19]

Initially, the units had little success with the smallest infants - those weighing less than 1500 grams (3.5 lbs.). Hyaline membrane disease or respiratory distress syndrome (RDS) remained a major cause of death among such infants until doctors discovered that the infants' lungs had not yet developed a substance known as surfactant which provided surface tension in the lungs' air sacs. Without surfactant, the tiny air sacs in the infant's lungs would collapse and stick together with each breath, causing respiratory distress. The development of continuous positive airway pressure (CPAP) ventilation allowed the infants' lungs to be expanded and contracted mechanically, without allowing their lungs to collapse completely, and as a result, more infants survived. [20]

Another important development occurred in the area of infant nutrition. Total parenteral nutrition (TPN) was designed to provide infants with all of their nutritional requirements entirely by vein, thus permitting the survival of many critically ill or premature infants who were unable to tolerate oral feeding or unable to absorb nutrients through their gastric systems. [21]

However, the use of these new technologies has caused iatrogenic problems in some infants. Infants who remain on ventilators for any length of time may become ventilator-dependent or may go on to develop chronic lung disease.[22] The prolonged use of TPN may lead to complications, including progressive liver failure.[23]

Recent developments in other areas of science, such as molecular physiology, are also being utilized in neonatal medicine. One such procedure is trace gas analysis - the study of exhaled gases which permits doctors to monitor an infant's digestive and metabolic processes.[24] Other new therapies which include high-frequency ventilation and extracorporeal oxygenation (ECMO), and diagnostic tools such as computed axial tomography (CAT) and magnetic reasonance imaging (MRI) are changing neonatal medicine.[25] In addition, new surgical techniques have made it possible to correct many congenital abnormalities, including serious cardiac defects.[26]

All of these developments have contributed to a steady decline in neonatal mortality rates.[27] For example, at the Hospital for Sick Children, Toronto, there has been a reduction in mortality of infants weighing less than 1,500 grams at birth from 85% to 21% between 1960 and 1982.[28]

B. Patient Characteristics

The major cause of neonatal illness and death is prematurity. Robert Usher writes:[29]

> Extremely premature infants have assumed an importance far outweighing their numbers. Only 0.87% of live births occur before 31 weeks; 0.85% weigh less than 1,500 grams ... Excluding deaths from lethal malformations, this gestational age group now accounts for 84% of neonatal deaths of all gestational ages. As many as 50% of the smallest survivors may be handicapped for life.

Another author reports that "[i]nfants born between twenty and twenty-seven weeks gestation have an eighty times greater likelihood of death than those born at term".[30]

A second major predictor of neonatal death is low birth weight. Infants weighing less than 2,500 grams are classified as low birth weight (LBW), while those weighing less than 1,500 grams are classified as very low birth weight (VLBW). Most LBW and VLBW infants are premature, however approximately one third of these infants are small although they are born after a normal gestation period. These infants are described as small for gestational age or SGA babies.

The third major cause of infant mortality are congenital abnormalities which account for approximately 20% of infant deaths. [31] It has been estimated that approximately 4% of all newborns are born with a major birth defect. [32] These abnormalities may arise from defective genes, chromosomal abnormalities and from environmental factors. [33]

Much of the decline in infant mortality rates is attributable to improvements in the survival of premature and low birth weight infants. However, the significant advances in these infants' survival rates have aroused concern, since studies have shown that these infants face increased risks of a variety of physical and neurological handicaps. [34] Paul Swyer, Director of the Division of Perinatal Medicine at Toronto's Hospital for Sick Children states: [35]

> Realistically, however, there must come a point at which medical care is defeated by natural incapacity, and many feel that the infant who is born

> less than 750 grams represents that point. Although survival rates of approximately 50% are possible for this group, the very high incidence of serious handicaps may be too high a price. However, must we then condemn the normal survivors? This is a serious question to debate.

Thus, the focus of neonatalogy in the late 1980's has shifted from ensuring mere survival of these infants to the quality of that survival.

C. Economic Considerations

Another aspect of the debate about the selective provision of neonatal intensive care is that of cost. Intensive care is the most expensive type of medical care and one recent estimate suggests that $100,000 is not an unusual bill for a premature infant. [36] An additional concern is the cost of providing long-term support to damaged survivors, which may run as high as $600,000. [37]

Some argue that saving lives is an ethical not an economic issue, that one cannot put a price on a human life. [38] However, this view has been considered by one economist and found to be untenable. Marcia Kramer explains: [39]

> [This] argument, humanitarian though it may seem, becomes increasingly weaker as it is carried to its logical extreme. Eventually, the moral principle that life should be sustained at any cost becomes inconsistent as the real cost of employing scarce resources to keep a particular person alive is measurable in terms of other lives ... A universally applicable NIC policy must provide for drawing the line on costs.

One Canadian study evaluated the economic aspects of the neonatal intensive care of infants before and after the introduction of a regional neonatal intensive care program in an urban industrial county in southern Ontario. 40 The infants were divided by birthweight into two classes: (1) 1,000 to 1,499 grams, and (2) 500 to 999 grams.

Providing neonatal intensive care to very low birthweight infants resulted in increased survival of these infants but also generated increased costs. The authors concluded that "[b]y every measure of economic evaluation, it was economically more favorable to provide intensive care for the relatively heavier infants (weighing 1,000 - 1,499 g at birth) than for those weighing 500 - 999 g." [41] However, a different conclusion was reached if only clinical outcomes were measured since the greatest increases in survival occurred in the 750 -

900 gram subgroup. Ironically though, neonatal intensive care for this subgroup produced the largest economic losses of any subgroup.

Similar results were obtained in a subsequent American study, in which a cost-benefit analysis was performed on the care of infants weighing between 500 and 999 grams at birth, who were admitted to the Women and Infants Hospital of Rhode Island between January, 1977 and December, 1981.[42] The authors "concluded that from the standpoint of cost-benefit analysis, neonatal intensive care may not be justifiable for infants weighing less than 900 g at birth."[43]

Nevertheless, society is often willing to pay for health programs which are not justified from a purely economic perspective, for example, organ transplantation programs and geriatric medicare. The benefits or positive effects of such programs may be humanitarian or social which are not measurable in terms of cost-benefit analysis.

However, scarcity of medical resources is a fact of life and neonatal medical programs must compete for scarce medical dollars with other patient groups and programs. Therefore, it is not unreasonable for health care policy-makers to utilize cost-benefit analysis as one tool to assist them in developing health care policies, provided it is applied to all health care programs.

Ultimately, policy decisions that certain treatments are too expensive to routinely provide are made at the government level by provincial health care ministries. In addition, individual hospitals may develop their own treatment policies (based upon cost-benefit considerations and likelihood of success) to provide particular treatments based upon predetermined criteria such as birthweight and gestational age.[44]

Policy decisions of this nature remove decisions in particular cases from parents and physicians by restricting the resources available for treatment. Although it is recognized that such policies are an important component of medical treatment decisions, this paper will focus on those cases which fall outside policy categories, for whom discretionary non-treatment decisions may be made.

III. Medical Practice

A. Development of Neonatal Intensive Care Units in Canada

The first neonatal intensive care units opened in Canada in 1962 at the Toronto Hospital for Sick Children and at the Montreal Children's Hospital. The marked success of these units in combating infant mortality and disability led to the establishment of neonatal units across Canada. Within Alberta, there are now four neonatal intensive care units in operation: The University Hospital and the Royal Alexandra Hospital in Edmonton and the Foothills Hospital and Peter Lougheed Centre of the Calgary General Hospital in Calgary.

Neonatal intensive care units are tertiary care units (Level III) offering the highest level of intensive care possible within a reproductive region. The units function as referral centres for the secondary (Level II), and primary (Level I) care units in a region, as well as providing care for normal infants within the local area.[45] Level I hospitals deal with normal or low risk cases and provide normal newborn care for these types of cases. Level II hospitals provide obstetric and neonatal services for normal patients as well as offering intermediate care for certain neonatal problems with a moderate risk, while Level III hospitals provide high risk care.[46] Non-specialized birth units routinely refer seriously ill infants to the neonatal care units since they lack the facilities and equipment as well as the highly specialized personnel necessary to adequately diagnose and care for many neonatal problems.

Neonatal intensive care is much more successful when it is offered in conjunction with obstetrical units capable of identifying and caring for women with high risk pregnancies.[47] However, in Canada the units are often established in hospitals which do not offer obstetrical care and thus many of the units receive all of their patients from other hospitals.[48]

Paul R. Swyer has written extensively on the organization of neonatal intensive care units. He cites the following statistics which he suggests should be used as "guidelines" in planning such units:[49]

> The incidence of risk pregnancies as judged by reasonably strict criteria is 10% of all births. Approximately 4.5% of live births will require skilled paediatric care and 3% will require intensive care for a period of many

> days. About 1% of live births will present with the most serious problems which can only be dealt with in a tertiary care (Level III, type C) centre having the special consultative services and facilities only to be found in a major pediatric centre. About four neonatal intensive care beds are required per 1,000 live births.

In Alberta, this would work out to approximately one hundred seventy-two beds.

In their research of the neonatal care system in Canada, Magnet and Kluge found the unequal distribution of the units within Canada to be a major problem, since it is difficult to gain access to the units from outlying regions. For, although all of the units are serviced by specialized road and air transport systems, by the time the problem is diagnosed and transport arranged to the neonatal unit it may be too late for some infants.[50]

B. The Role of Neonatologists and Other Team Members

1. The Neonatologist

Neonatology is a team orientated discipline and the head neonatologist may be seen as the team's captain, whose primary responsibility is the supervision of all aspects of a wide-ranging number of problem cases involving newborn infants.[51] His other functions consist of "coordinating the complete neonatal team, evaluating new equipment, overseeing neonatal residents and interns, scrutinizing new developments in the field," and communicating highly complex and technical medical information in a way that can be understood by infants' frightened parents.[52] The neonatologist may also attend high-risk deliveries and have ongoing research and teaching responsibilities.

In some neonatal intensive care settings there may be overlapping clinical and administrative responsibilities which are jointly shared by an obstetrician-perinatologist and a pediatrician-perinatologist (neonatologist) who act as co-directors of the neonatal intensive care team.[53]

Once the infant is admitted to the neonatal unit the neonatologist assesses the infant's condition and decides which specialists to involve in the case. The number and type of specialists who become involved depend upon the nature of the child's anomalies. Decisions are made about the child's care upon completion of the various specialists' reports.[54]

2. The Nurses

Nurses who work in neonatal intensive care units have difficult jobs. They face conflicting pressures from physicians and parents as well as the constant pressures which attend the responsibility of caring for high risk infants.

The ratio of nurses to infants may be 1:1 for seriously ill neonates, while other neonates can be cared for by one nurse for two infants. Intermediate nursing care would consist of one nurse to three infants. [55]

Nurses maintain close contact with the parents and are expected to provide information and emotional support. Parents who are upset and angry may vent their frustrations and angers on the nurses, which contributes to the stress of the job.

Although nurses are routinely present and participate in conferences between doctors and parents, they will occasionally disagree with the decisions of doctors and parents to continue or withdraw certain treatments. [56] Withdrawing treatment can be particularly stressful for the nurses who disagree but must continue to care for the infant until it dies.

The high rate of deaths as well as the uncertainty and anguish which accompany many decisions causes many nurses to experience depression and burnout and as a result there is a high turnover in the nursing staff of neonatal intensive care units. [57]

3. Medical Consultants and Support Personnel

Medical consultants who are called in by neonatologists may include pediatric specialists such as neurologists, cardiologists, urologists, endocrinologists, dermatologists; surgical consultants, such as neurosurgeons, cardiac surgeons, orthopedic surgeons, and anesthesia consultants. [58]

Other special services may include "radiology, biochemistry, pathology, microbiology, biomedical engineering," as well as support services which include "respiratory therapists, physical therapists, pharmacologists, lab technicians, chaplains and social workers". [59]

C. Current Medical Practice

1. Introduction

Twenty years ago decisions to let handicapped infants die were essentially private matters between physicians and the parents involved. Very little was known outside the medical community about these decisions or the reasons which led to them.

The problem which has plagued non-medical writers who have been debating the legal and ethical questions as to whether, and when, it is permissible to let defective infants die has been a lack of information regarding actual medical practices. Although Duff and Cambell's article provided the impetus to public debate of this issue, the authors provided information on the frequency of selective non-treatment in only one neonatal intensive care nursery.

However, medical practices in this area have become more visible and have been subject to a great deal of public attention in the past few years for a number of reasons.

1. There have been several well publicized cases in the United States, Britain and Australia in which treatment was withheld from defective infants.[60] Here in Alberta, a young Israeli pediatric resident was alleged to have caused an infant's death by ordering a lethal dose of morphine. Although an inquiry concluded that the cause of the infant's death was uncertain, the case generated a considerable amount of public controversy.

2. A number of non-medical writers have spent time as participant observers in neonatal care nurseries and have published accounts of the process of decisionmaking as well as the decisions made by physicians and parents on behalf of the infants in these nurseries.[62]

3. Surveys have been conducted in the United States, Canada and Australia regarding the attitudes and practices of physicians with respect to the treatment of defective infants.[63]

4. Medical doctors themselves have spoken out at seminars and have written articles describing their treatment practices.[64]

5. Certain parents have described their perceptions of medical decisionmaking practices with respect to the care and treatment given to their seriously ill infants.[65]

This section of the paper will focus on medical practices as described by the results of these surveys and the descriptions of non-medical writers who spent time observing practices in neonatal nurseries. Some comments should be made about this information:

1. The non-medical writers whose views are examined here have described the medical practices at particular nurseries and their findings may not be true for all neonatal nurseries.

2. Although the surveys to be discussed reveal general similarities in the attitudes and practices of physicians regarding selective non-treatment of certain infants, some commentators have criticized those who use these types of surveys in support of the view that widespread non-treatment exists. They argue that the data presented by these surveys have never been adequately validated. [66]

3. This criticism has also been raised by a number of physicians who have participated in these surveys, many of whom commented that when confronted with an actual situation, they might react very differently from the way they indicated in the survey questionnaire. [67]

4. Other physicians who participated in a survey which provided hypothetical cases "doubted whether the case histories defined in sufficient detail the complexities of the clinical situation which physicians actually face." [68]

Thus, the findings of these surveys should be viewed with some caution. However, two of the surveys deserve particular mention: One is Diana Crane's survey later published as a book entitled, The Sanctity of Social Life: Physician's Treatment of Critically Ill Patients, and the other is Joseph Eliot Magnet and Eike-Henner Kluge's survey of neonatal care practices in Canada which appears in their book, Withholding Treatment from Defective Newborn Children.

(a) The Crane Survey

Professor Crane's survey, although done several years ago, is still the most comprehensive survey to date of the treatment of critically ill patients. What differentiates her survey from the majority of other surveys in this area is that she attempted to validate the survey responses by reviewing the hospital records of the infants in the pediatric nursery in question in order to determine what the doctors actually did when faced with the types of cases specified in her survey.

Her survey covered the treatment of older patients as well as infants, however she found that the most controversies over treatment occurred in the neonatal nursery where difficult cases appeared to be the norm.

In the area of neonatal practice she presented typical case histories which dealt with the treatment of infants born with congenital anomalies and severe birth defects. The questionnaires were given to three groups of pediatric physicians - pediatricians, pediatric heart surgeons, and neurosurgeons with the respondents being asked to indicate whether they would provide treatment to the infants in question.

Professor Crane initially examined differences in treatment that would be given depending on the nature of the infants' anomaly. Children with physical problems were treated more often than those with mental disabilities in the survey.[69] Another important factor according to the survey responses was family attitude towards treatment. Physicians appeared to be much more influenced by parental attitudes in decisions to withhold treatment from infants who were mentally deficient than they would be in cases where the child suffered a physical abnormality.

She then attempted to validate the survey answers given by the pediatric heart surgeons in response to a group of questions concerning their willingness to perform cardiac surgery on Down's Syndrome children suffering from, in one instance, a moderate heart defect and in another instance, a severe heart defect. They were asked if they would usually operate in situations in which the families wished to have the surgery done and also what their response would be where the family was unfavourably disposed to having the surgery performed. In cases where the family attitude was favourable, 59% of the pediatric heart surgeons said they were willing to operate on a mongoloid child with a moderate heart defect (tetralogy of Fallot), while 50% said they would be willing to operate on a mongoloid infant with a severe heart defect (atrio-ventricular canal). Where parental attitudes were unfavourable, which was indicated by the child being institutionalized, the percentages of surgeons willing to operate dropped to 18% for the moderate defect and to 12% for the severe defect. [70]

A review of the hospital records of all mongoloid children with heart defects over a five year period was conducted at the hospital where most of the interviews had taken place. During this period, thirty-nine percent of the mongoloid children with heart defects had received surgery while sixty-five percent of the non-mongoloid children with similar heart problems had been operated on. [71]

Breaking the figures down further, Crane found only one Down's Syndrome infant had the moderate defect (tetralogy of Fallot); the more severe defect (atrio-ventricular canal) was the most common, being diagnosed in 14 cases (42% of the group). Only one child in this group was institutionalized while the other children lived with their families. Since it appeared that these families had sought treatment for their children, Crane assumed that they presumably were in favour of the surgery. Yet the hospital records showed only thirty-one percent of these children were operated on, which suggested that these operations were performed less frequently than indicated by the results of the survey. Moreover, these decisions were made in a hospital which had a clearly stated policy of giving equal treatment to mentally handicapped children.

Although she recognized that her sample of mongoloid children was small, Crane submitted that the results appeared to show that doctors were more influenced by social variables than medical variables in their decisions to operate in these kinds of cases. Thus, physicians view a patient as treatable if he or she has the potential to establish social relationships with others. Since many physicians perceive mentally retarded infants as lacking the potential to establish meaningful social relationships, they will be less likely to treat these infants than infants who are physically damaged.

She obtained similar results in analyzing cases by physicians in other specialties and concluded that: [72]

> In general, the findings concerning the attitudes and behavior of physicians towards these types of patients were remarkably consistent in the various samples. The consistency of the findings using examples from four different specialties and at both ends of the life cycle is an important element in their credibility.

(b) Magnet and Kluge's Study

This study is important because the authors went far beyond sending out questionnaires and hypothetical case studies. They conducted extensive interviews of approximately 200 doctors, nurses, residents and social workers as well as prosecutors and officials from Children's Aid Societies. Their intention was "to paint a detailed picture of what really goes on inside" the units and "to elicit reactions and responses that would give the feel of actual intensive care practice." [73] By conducting their study in this fashion, using investigative journalism techniques of asking open ended questions calling for descriptive answers, they were able to gain a clearer picture of the actual decisionmaking processes within the units than would have been possible using the survey method which by necessity places constraints on the respondents' answers.

This study is important as well because its findings are not limited to a particular hospital. The authors visited every neonatal intensive care unit in Canada and their findings apply to all of the units.

Magnet and Kluge's major findings (which will be discussed in greater detail in the following section) were that:

1. Passive euthanasia is routinely practiced in Canadian neonatal units, but it is practiced in a haphazard manner in an atmosphere of uncertainty and tension;
2. Defective infants are often permitted to die by starvation and/or dehydration;
3. Medical information is often presented in a selective fashion to parents;
4. Doctors admitted to recommending treatment for some infants whom they would not wish treated if they were the parents.

These findings led the authors to conclude:

1. The law should be changed to permit the killing of seriously defective infants, which the authors described as "suicide by agent";
2. This decision should be made by the parents;
3. The criteria used in making such a decision should be whether the child has the potential for a life of acceptable quality (determined by the parents); and
4. The termination of an infant's life should be carried out by doctors in a quick and painless fashion.

Magnet and Kluge's findings and conclusions have been vehemently criticized by the medical profession. The Canadian Pediatric Society described the authors' recommendations as "grossly misguided" [74] and made without consideration for the value of a human life. Dr. John Watts, Chairman of the Society's bioethics committee, further argued that the study "has chosen interviews carefully, made generalizations and then not proved or justified them in any way." [75]

Whether or not one agrees with the authors' findings/conclusions, the study cannot be ignored because it is thus far the only Canadian study of this issue. All of the other surveys have been done in the United States, with the exception of one Australian study, and one must be even more hesitant in applying their findings to the Canadian experience.

2. Issues in Neonatal Medicine

(a) Passive Euthanasia

Virtually every survey [76] as well as articles by clinicians such as Duff and Cambell, Lorber and Shaw, have shown that physicians actively treat most infants while withholding treatment from others with a poor prognosis. [77] However, there is little consensus among physicians apart from the most extreme cases, about what conditions or criteria justify withholding treatment.

What is not known is how frequently selective non-treatment occurs. There are at present no current reliable data as to the extent of the practice. In a newspaper interview, however, E.H. Kluge estimated "that more than 100 radically defective infants are allowed to die or even assisted in dying in Canadian hospitals every year." [78]

(b) Active Euthanasia

There is far greater consensus with regard to the practice of active euthanasia. Diana Crane found responses to a question in her pediatric questionnaire regarding the direct killing of an anencephalic infant to be "overwhelmingly negative". Only 1% of the respondents (residents and physicians) said they would be likely to give an "intravenus injection of a lethal dose of potassium chloride or a sedative drug" to an anencephalic infant; while 3% said they might do so." [79] She found a similar antipathy towards active euthanasia among other specialties as well and concluded that while passive euthanasia with respect to certain patients is widespread, active euthanasia was relatively rare, as a result of "a very strongly held norm in the medical profession against direct killing." [80]

A similar conclusion was reached by Singer et al. in an Australian survey of the attitudes and practices of obstetricians and pediatricians who responded to the question of whether it can ever be right to take active steps to terminate an infant's life. Thirty-one percent of the obstetricians accepted active euthanasia in principle while 69% thought it was never permissible. Of the pediatricians, 40% were willing to accept active euthanasia but most (55%) were against it. [81]

Somewhat different responses were given by 20 participants at the Somona Conference on Ethical Issues in Neonatal Intensive Care. In response to the question, "Would it ever be right to intervene directly to kill a self-sustaining infant?", seventeen answered yes, two said no and one was uncertain. [82] What is important to note about the yes responses is that many of the physicians who answered yes indicated that they would not do it themselves but would not condemn someone else for doing so, while others said their yes response "was intellectual, but that they were emotionally uncomfortable with the action." [83]

Magnet and Kluge claim to have documented two types of euthanasia in Canadian neonatal units. The first is a gradual increase in the amount of a painkilling drug such as morphine which is given to relieve pain, though it is known that the administration of the drug will hasten the infant's death. [84] This appears to be a well-recognized medical practice. Morphine is administered in this manner to infants who are terminally ill in order to minimize their pain and suffering.

They suggest however, that in some instances, this type of euthanasia can cause tension in the unit since doctors order the painkilling regimen but nurses have to administer it. Nurses may feel anxiety or guilt when ordered to administer a painkilling medication to an infant who is in apparently no pain or sleeping, since they realize the medication is not medically indicated. This practice contravenes the Canadian Pediatric Society's Policy Statement on the treatment of defective newborns which states: "the use of painkillers in order to hasten death is forbidden and the use of sedatives to keep a child asleep so it doesn't have to eat is also forbidden." 85 However, administering painkillers in order to minimize pain during a terminal illness though it may have the added effect of shortening a patient's life is permissible. The distinction lies in the physician's purpose or intention in administering the drug.

A second type of euthanasia which is practiced, according to Magnet and Kluge, (though they admit they have no idea how often it happens) is that a "doctor or nurse may hold back part of the morphine dosage recorded as administered. When a sufficiently large amount is collected a lethal dosage will be administered all at once, causing cardiac arrest and death." 86

Insofar as administering lethal doses of other non-therapeutic drugs it would appear to be extremely difficult to escape detection. Fred Frohock, a political scientist who spent several months as an observer in a neonatal intensive care unit in the Northwestern United States, discussed acts of omission and commission within the unit with one of the staff neonatologists who commented: [87]

> In terms of acts of commission, I think about the only thing we do from time to time is sedate children with some painkiller, morphine or whatever, that may in some children suppress respiration. It's very difficult to separate the purported therapy from the vehicle [of death] in those cases.
>
> In terms of using insulin or potassium or anything else like that as an active thing, there's no way in the world in an intensive care setting that everybody and their brother won't know you've done that. And so that's the impossible thing to do.

There has been only one reported instance of a doctor killing an infant in Canada. In a case mentioned earlier, Dr. Maurre Nachum Gal, a young visiting Israeli physician ordered a lethal dose of morphine (50 times the recommended dose) for an infant who was suffering from convulsions due to brain damage sustained prior to her birth. [88] The infant was dying and in pain and Dr. Gal later admitted to ordering the lethal dosage because he couldn't stand to see the baby suffer. However, this type of mercy-killing would have to be extremely rare within a Canadian neonatal intensive care unit for a number of reasons.

First, two nurses were aware of the order. The nurse who received the order and who was supposed to administer the drug immediately saw that the dosage was extremely high. In accordance with hospital policy she showed the order to her supervisor who agreed with this conclusion. The supervising nurse then took the order back to Dr. Gal requesting clarification of the dosage. He reduced the dosage from 20 milligrams to 15 milligrams, still an excessively high dosage for an infant of that size. She took the morphine and instructed her subordinate to administer the dosage. The nurse administered the injection and the infant, Candace Taschuk, died within half an hour.

Routine cellular and physiological autopsies were done but no toxicological examination was ordered, which would have shown the high levels of morphine in the baby's system. The autopsy confirmed that the injuries suffered by the infant prior to birth were fatal and the death was recorded as natural and expected. The hospital pathologist did not see the drug order on the doctor's order sheet.

During the course of a routine review of the infant's death by the hospital's Perinatal Mortality Review Committee, the order for the "massive and unusual" dosage of morphine was discovered and hospital officials immediately advised the Medical Examiner's Office. The Medical Examiner contacted the physician's registrar and the Edmonton Police and separate investigations were subsequently conducted by the Medical Examiner's Office as well as the Police.

The registrar of physicians immediately summoned Dr. Gal who confirmed his actions. His license to practice medicine in the Province was immediately suspended and a formal college hearing into the affair was ordered. A few days later, Dr. Gal fled the country and went back to Israel.

Because of a lack of evidence - the infant's body had been cremated and no toxicological tests had been performed, no criminal charges were laid. Instead, a Fatality Inquiry was ordered to look into the cause of death and to recommend ways of dealing with such cases in the future. Ultimately the Inquiry was unable to determine the cause of death due to conflicting medical testimony.

However, information about standard medical practices in a neonatal intensive care unit was revealed during the course of the Inquiry. Normally a number of checks within the system would ensure that this kind of an order would not be implemented.

In his report, Judge Rolf "observed that the maximum dosage per weight of the recipient is uniformly accepted in the medical field" but each hospital would have a policy with respect to the use of narcotics. [89]

The University Hospital's Neonatal Intensive Care Unit Drug Handbook indicated the dosage of morphine for an infant such as Candace Taschuk to be 0.05 - 0.1 milligrams per kilogram of weight. Its indicated use is for post-operative analgesia and its side effects are listed as hypotension (low blood pressure) and respiratory depression. The Handbook also requires that a physician must be available on the unit when administering the medication. [90]

Both nurses involved in this case were experienced nurses and they testified that they knew that the dosage ordered was excessive. They followed the hospital's policies to a point; initially, by the administering nurse advising her supervisor and subsequently, by the supervising nurse questioning the physician about the order. But neither of the two nurses then made any attempt to check the order with another physician on the unit which Dr. David Schiff, the neonatal unit's director, testified should have been done. Had he been so advised, he stated that he would have immediately countermanded such an order.[91]

In addition to following hospital policies, each nurse, knowing that the order amounted to a lethal dosage, had a professional obligation to refuse to follow the order. Simon Renouf, the executive director of the United Nurses of Alberta, testified at the Fatality Inquiry that a nurse is not committed to follow a doctor's order if she thinks that order is improper.[92]

Apart from violating her professional ethics with the possible disciplinary sanctions that would be imposed by the nurses' governing body (in this instance the Alberta Registered Nurses Association), the potential threat of criminal prosecution would be an added deterrent. 93 Thus, it is likely that in the great majority of cases that nurses would refuse to implement such an order.

Another reason such an event would be unusual is the further possibility of detection by the hospital pathologist who would receive the infant's chart prior to performing the autopsy. If a pathologist discovers a potentially fatal dosage he is required by law to contact the Office of the Medical Examiner who would then require a toxicological examination. One problem for the pathologist reviewing the charts is that they can run into hundreds of pages making it difficult to detect this type of error. Judge Rolf therefore recommended that prior to autopsies being performed, the doctors' order sheets should be brought up to date and then reviewed by the pathologist. 94

Another safeguard is the Perinatal Mortality Review Committee which routinely reviews infants' deaths. 95 The infants' charts and the results of the autopsy findings are examined. It was in the course of preparing the infant's chart for examination by the Committee that one of the hospital neonatologists discovered the unusual dosage and immediately took action.

In view of the strongly held medical ethic of "preserving life" as well as the numerous safeguards in place within the hospital setting it is submitted that cases of active euthanasia in Canadian hospitals are relatively rare, isolated events.

(c) Admission to the Units

Most infants who are candidates for neonatal care are born in hospitals without such units. Consequently, they must be referred to the units from their birth facility. Decisions to refer such infants may be joint decisions between the parents and the attending physician (sometimes with input from other hospital staff) or they may be made by the physician alone depending on the urgency of the situation and/or the parents' emotional state.[96]

If the parents refuse their consent to a referral the doctors will explain to them the advantages and most parents will go along with the recommendation. When the parents are intractable, physicians may resort to a number of coercive techniques to obtain their consent ranging from presenting selective information, pressuring them to consent by telling them to take the infant home to die or in rare cases, threatening them with legal action. In most cases compliance is obtained without resorting to legal action. [97]

The attending obstetrician or pediatrician will call the NICU to discuss the case with a neonatologist. A decision to admit the infant is based upon "the inferred viability of the baby (weight plus gestational age combined with a number of clinical signs like heart and respiration rate) and, in marginal cases, the attitude of the immediate family." [98]

Frohock found that admission decisions to get into the nursery were governed by the principle of triage, in which babies who can benefit the most from treatment or who have the best chance of survival will be admitted. However inside the nursery, decisions regarding treatment "are made on the basis of who needs the therapy the most, so that the sickest babies get precedence." [99] He explains the reason behind the principle for admission is scarcity. Not all infants can be admitted into the nursery. There is simply not enough space. However once in, there are usually the requisite items necessary to accommodate most required therapies. [100]

Upon admission, the infant becomes a patient of the neonatologist, who assesses the infant's overall condition. The neonatologist may decide the infant is salvageable and may institute active treatment himself, or he may consult with other specialists prior to making a determination. On the other hand, treatment may be deemed to be futile and thus active treatment may be withheld. When this occurs, the baby may be cared for in the unit until death or in some cases may be returned to the referring hospital to die.[101]

(d) Communication with Parents

The most common and widespread criticism of NICU medical practices is in regard to the information that is communicated by physicians to parents. There is a basic inequality between the parents and physicians regarding decisionmaking since physicians possess the information essential to making an informed decision regarding the child's treatment.

Magnet and Kluge found that most neonatal units attempt to keep in close contact with the parents by daily phone calls or personal meetings. However, these efforts may be hampered by circumstances; the family may live a long distance away from the unit making efforts to communicate more difficult,[102] parents with different cultural and educational backgrounds may have difficulty understanding the information being transmitted,[103] personality clashes can arise between parents and physicians due to stressful circumstances,[104] and parents and physicians may have different values regarding acceptable outcomes of treatment.[105] Another barrier to communication arising out of the circumstances in which decisions have to be made, is that "there are so many interrelated decisions about care that have to be made on a continuous basis that it is hard to convey all the relevant facts and probabilities to anyone not constantly involved in the situation."[106]

While circumstances may exacerbate communication problems between parents and physicians, parents often believe that information is being unnecessarily withheld. Paul and Marlys Bridge's infant son was treated in a Canadian NICU. While they believed their son received excellent treatment they were frustrated by the amount of information they were given, in comparison to the information they perceived other parents getting. They wrote:[107]

> We were also dissatisfied with the amount of information we were able to obtain about Christopher's condition. Aside from one occasion when we were permitted to see a few pages of the hospital records relating to the first two days of Christopher's life, we were denied permission to look at his hospital records because this was against "hospital policy" - an argument that apparently brooks no opposition. We did get detailed verbal updates on our son's condition, but not as many as we would have liked. Our distress was compounded by our awareness that other parents with children similar to Christopher were obtaining access to their children's records with their physician's permission.

Frohock and Magnet both point out that physicians are usually willing to "fairly and lucidly" describe the various options so that parents are able to make a choice. However, physicians do not always present the complete picture; often information may be selectively presented particularly when physicians have reached their own decisions as to the proper course of action in a particular case. Under these circumstances the information will be presented in a manner designed to steer parents towards that option.[108] Frohock cites examples of this approach:[109]

> ... by labeling a therapy as "experimental" or "untested" or "new and radical", a doctor can be reasonably sure of a negative response. If the negative choice is

> still not forthcoming, the doctor can say the therapy is "unknown" or of "marginal benefit" or has "unpredictable side-effects." On the other hand, if a doctor describes a therapy as "promising" or "improved" or "hopeful" or "quite possibly effective", the parents are more likely to select that treatment ... .

Physicians are not being intentionally devious in presenting information in this fashion. Rather, their intention is to ensure that parents will make the "right" decision based on the physician's best medical judgment, or as Magnet and Kluge explain: [110]

> They superintend the decisional process in order to ensure that the parents do not deprive a salvageable baby of help, or force treatment on the hopeless case.

However, by effectively limiting or controlling the information that parents receive physicians can ultimately control the decisionmaking process. Helen Harrison discusses the role of parents in NICU decisions and argues that this approach places parents in a position of "powerlessness" and leaves them at "the mercy of the philosophies and motives of their physicians." [111] Furthermore, she contends that the attempt to control the information given is misguided as it, [112]

> mistakenly assumes a kind of omnicompetence on the part of the NICU staff, who view themselves as bringing to bear their professional expertise from a 'detached and objective position in order to more adequately assess the child's best interests.'

Regardless of the intention behind the selective presentation of information it reveals a lack of awareness on the part of practitioners of the parents' right to a fully and freely informed consent to their child's medical treatment.[113] This may however, stem from the relief that parents are unable to be fully informed in order to make reasoned decisions about medical treatment shortly after the birth of a seriously ill or defective child.[114]

(e) Who Makes the Decision?

Magnet and Kluge contend that there is an established medical consensus in neonatal intensive care that doctors are the proper decisionmakers with respect to initiating or withholding life-saving medical treatment. In support of this view they cite numerous examples from their research in which doctors reserve decisionmaking authority. Among the decisions which are made by physicians are: decisions to refer infants to neonatal intensive care units, decisions with respect to initiating or discontinuing ventilation, refusals to treat when parents request, and resorting to legal action to allow treatment over parental wishes.[115]

However, these examples do not tell the complete story. In most cases, once the physicians have reached some tentative conclusions they discuss the facts and their opinions with the parents to try and come to a mutually agreeable decision.

A number of physician surveys suggest that in ambiguous cases physicians are willing to respect parental wishes to either treat or withhold treatment. As discussed earlier in Diana Crane's survey, physicians were much more willing to operate on Down's Syndrome infants with a heart defect when parents were in favour of the surgery. Later, in a Massachusetts survey, pediatricians were asked if they would recommend surgery for a Down's Syndrome infant with a duodenal atresia and where parents refused surgery. Fifty-one percent of the pediatricians responded that they would not recommend surgery.[116] A similar question was put to pediatric surgeons and pediatricians in a nationwide U.S. survey. Eighty-five percent of the surgeons and 65% of the pediatricians said that they would acquiesce in the parents' refusal to consent to surgery (to remove an intestinal blockage) in a Down's Syndrome infant with congenital heart disease.[117]

There are cases however, where doctors will not go along with parental wishes. This can occur in two different situations. The first, is where the parents push for treatment when doctors believe treatment should be withheld. Doctors reserve the right not to treat when they consider treatment is unwarranted. [118] In her survey, Diana Crane included a question designed to test physicians' responses to family pressure in giving a medically futile treatment. The example involved the case of an adolescent who had broken his neck and become a quadriplegic. The operation, a cervical fusion, is considered of little value because the possibility of it improving the patient's condition is estimated to be a one in five thousand chance. In response to the question of whether they would usually operate in such a case, 7% of neurosurgeons answered they would in a case where the family applied no pressure, while 9% said they would when the family pushed for surgery. [119]

When parents push to have everything done doctors may not directly say no, yet still may refuse to actively treat the infant. A neonatologist explains how this may happen: [120]

> Set up a theoretical case. For instance how about a baby born at 400 grams, twenty-four weeks of gestation,

> who's got a heartbeat of 110 and gasping with expiratory effort. Parents want everything done. Well, everything done and full court press means putting in arterial lines, intubation, ventilation, and a number of other things we can throw in for the child. In the process of explaining to the parents the non-viability of the child, what we generally do is put some of the tubes in but do not necessarily hook up the machine ... [or perhaps] ... there's a foot dragging of ten minutes ... Maybe it's hard to get the machine up. We can do things short of ventilation. You could put a tube in. You could ventilate by hand, for instance, and if there's no significant response with that, you could say to the parents, "Well look there's no response. Therefore ventilation will not be able to do anything more than we've done by handbagging. Therefore, we will not commit this piece of equipment. Okay? But we'll maintain the baby short of that.

The second situation in which doctors may override parents' decisions occurs when parents refuse to consent to treatment that doctors believe is clearly indicated. They may apply pressure on the parents in order to obtain their consent, by explaining the benefits and possibilities of the proposed treatment or in rare cases, they may resort to legal action. Upon receiving the substituted consent treatment may then be given. [121]

Finally, it is not always clear who makes the decision. One pediatrician who took part in Diana Crane's survey wrote: [122]

> 1. The individual physician may not make the decisions at all ... they may be forced by the availability of information to the entire community, by previously agreed staff policies, by the desire of the patient's parents to bring the infant to a known activist center, by the commitments undertaken during the diagnostic evaluation of the infant's status in looking for a correctable lesion, by the arrival of the anesthesiologist with his damn machine before your own arrival, etc.
>
> 2. Or the decision-making process may be so interwoven with the process of education of the parents and dealing with the parents' confused sense of responsibility for decision-making and underlying guilt that it is very unclear exactly when and by whom the decisions were made, even though the physician then announces them as being his own.

(f) Procedure for Decisionmaking

Once an initial assessment is made of the infant's condition by a neonatologist an attempt is made to stabilize the infant in order that additional data can be obtained to ensure a more accurate diagnosis. Other pediatric specialists may be consulted and each will assess and report on the functioning and prognosis of the infant's various systems.

Magnet and Kluge point out that while the neonatologist retains formal responsibility for the decisions the established procedure calls for consensus decisionmaking with other members of the neonatal team. The consensus approach may be altered in some instances where the prognosis for one system is extremely poor. In such cases the ultimate decision will depend upon the assessment of the relevant specialist.[123]

Decisionmaking is also influenced by input from the nurses who care for the infants on a daily basis.[124]

(g) Criteria for Decisionmaking

(i) Medical Criteria

Treatment decisions in neonatal units do not merely involve a choice between giving either "treatment" or "no treatment". Physicians may choose from a range of possible treatments in some cases and may give certain treatments while withholding others. Decisions regarding treatment involve a consideration of patient and treatment characteristics.[125]

The primary criterion in terms of the infant's characteristics is the anticipated quality of the infant's life. The quality of life is determined by assessing "the child's potential for physical and mental development and environmental factors which bear on the potential for development." [126] Both the severity of impairment as well as the probability of impairment are considered in the assessment.

The most important medical indicator is the infant's potential intellectual capacity. Frohock writes, "neurological functions are not merely first on an ordinal listing of quality of life conditions. They dwarf all other conditions in cardinal magnitude." [127] This same view is echoed by Magnet and Kluge who state: [128]

> Special mention should be made of mental retardation. Properly speaking, mental retardation is a medical factor - nevertheless, retardation is such an important consideration in doctors' minds that it transcends the purely medical. There is widespread discomfort and fear provoked in many doctors, paramedical staff and parents by retardation. Even a mildly handicapping situation can become ripe for a decision not to treat if retardation is a factor.

In addition to neurological considerations, another important factor is the capacity of the child to live apart from the medical technology that supports his or her life. An example would be infants who become dependent upon respirators to sustain their breathing.

Cases in which the infants will have no serious or long lasting mental or physical impairments are always treated. However, there is controversy about the appropriate levels of treatment to be given in two situations. The first is where there is a high probability of impairment, although the impairment is not seen as being extremely severe, while the second situation arises where there is a high degree of uncertainty of future impairment, but the impairment would be severe. An example of the first situation might be a Down's Syndrome infant with a duodenal atresia while the second situation might involve a premature infant who has suffered bleeding in the brain.[129]

In her survey, Betty Levin found that most respondents would not provide as aggressive levels of treatment for infants in the above situations as they would for infants who would be expected to survive without any serious or lasting defects.

Levin also found controversy with respect to "the use of the most aggressive treatments (such as organ transplants and extra corporeal membrane oxygenation, which are very invasive, costly and/or experimental) for any baby, and also about the use of some relatively ordinary treatments (such as IV feedings) for some infants who are terminally ill." 130

Treatment, in some cases, may also be instituted or withheld on the basis of standardized medical criteria rather than being assessed on a case-by-case basis. For example, some hospitals will not ventilate infants who are below a certain weight, less than a certain gestational age or below a certain Apgar score. 131

Treatment choices may also be made by physicians which are not based upon any substantive criteria. Firstly, treatment may be given without a clear reason. In her survey, Diana Crane interviewed respondents who had indicated that they would treat ancephalic infants. When asked to explain why they would treat such infants, most were unable to suggest a basis for their decision. She concluded: 132

> Few of them could offer an explicit rationale. In general, it appeared that those who would treat such a child

> did so because the idea of completely withdrawing therapy was simply unthinkable. Very few doctors seemed to have given such matters enough consideration to have worked out a philosophical position toward them.

Secondly, some decisions may be made by default. For example, a pediatric resident discussed a case in which a child with severe problems was repeatedly resuscitated when the child had a cardio-pulmonary arrest: 133

> We discussed whether or not to resuscitate. Each time we discussed it, we were unable to make a decision so that when the child stopped breathing we did resuscitate because we hadn't decided not to.

(ii) Non-Medical Criteria

The most important non-medical criteria affecting treatment decisions of defective infants are the parents' attitudes. Quality of life considerations are interpreted in light of the willingness of the parents to accept and care for the child. Parental wishes carry the most weight in cases in which it is unclear based on purely medical criteria whether treatment should be initiated, continued or withdrawn.[134]

Other non-medical factors which may affect treatment decisions include the following: the parents' marital status, the quality of the child's family (determined by the parents' intellectual capabilities, psychological factors, ability to provide adequate care), possible adverse effects of the child on the family (parents' marriage, effects on siblings), family finances, ability of parents to have additional children, adequacy of institutional care if parents refuse to care for the child, opportunity to learn, practice or teach new techniques, the feelings of hospital staff providing care to the child and costs to society. [135]

Although non-medical data is used in Canadian neonatal units, Magnet and Kluge found no consensus regarding methods of acquisition of such data, how the data is used, or control over quality of the data obtained. [136]

Medical decisionmaking in neonatal units is not an event in which a life or death decision is made, but is rather a process which may involve a series of choices, balances and compromises which are made in response to the infants' perceived best interests which may change over time. Physicians do not always know the consequences of alternative courses of action and their responses to the problem of uncertainty will depend on a number of factors, "including the individual physician's philosophy and degree of experience, the role of the parents, the prevailing moral, economic and legal climate, the accessibility of resources and the degree of involvement with a baby." 137 Thus, the longer the infant lives, the greater will be the effort to save him and the greater the certainty required before treatment will be withdrawn because he has become a member of a family and the medical personnel may have developed a relationship with him. 138

(h) Management of Infants Selected for Non-Treatment

Once it has been decided not to pursue active therapy for an infant, the question which arises is whether 'any' effort should be made to maintain the infant's life. Magnet and Kluge found a consensus within Canadian neonatal units that such infants should be fed, have their fluids managed and be kept warm. The practice is to make the baby comfortable but no other treatments such as surgery, resuscitation or antibiotics are given. 139

There is less agreement over the administration of painkillers to neonates since not all physicians believe their nervous systems are developed enough to experience pain. Thus, practices in this regard may vary between units and among physicians.[140]

3. Treatment Debates in the Medical Literature

A number of neonatologists, pediatric surgeons and other pediatric specialists have debated the issue of withholding treatment from seriously ill newborns. Within the medical literature there has been a great deal of discussion with respect to two types of congenital anomalies:

(a) Down's Syndrome

Down's Syndrome is the most common major congenital malformation which occurs approximately once in every 700 births. Individuals with the syndrome are retarded although the degree of retardation is impossible to determine in infancy. Often these infants suffer from serious physical defects associated with the condition. The most common problems are congenital heart defects and esophageal and duodenal atresias (blockages). These defects can often be successfully corrected with surgical treatment although the underlying mental impairment is unaffected. Failure to perform the surgery to remove an atresia will result in the infant's death. Surgery has often been withheld from these infants because of the Down's Syndrome and the medical literature has considered the physicians' obligations when the parents' and infants' interests conflict.[141]

(b) Spina Bifida Cystica

Spina bifida is a defect caused by the failure of the neural tube (forerunner of the brain and spinal cord) to close during the first month of pregnancy. The cystic swelling may involve the meninges (meningocele), the spinal cord (myocele) or the most serious form involving both (meningomyelocele).[142]

The severity of the condition depends upon several factors, including the size of the lesion, the location of the defect along the spine as well as the presence of associated congenital anomalies. Hydrocephalus is commonly associated with meningomyelocele (also known as myelomeningocele) and involves an enlargement of the head which is caused by an accumulation of cerebrospinal fluid in the ventricles of the brain which may lead to brain damage from pressure on the neural tissue. Treatment involves the implantation of a shunt to drain the fluid away from the brain. In addition to hydrocephalus, infants with this defect may be totally or partially paralyzed below the defect, be unable to control their bowels and bladder, and may have spinal and hip deformities.[143] A number of treatment decisions must be made for infants suffering from spina bifida which include,[144]

> surgical closure of the spinal lesion ... shunting and other surgical procedures for neurological problems, control of infection and whatever surgical procedures may be necessary for orthopedic and urological abnormalities.

Disputes have arisen amongst clinicians treating spina bifida with respect to the criteria used in selecting infants for treatment/nontreatment, the management of those infants selected for nontreatment and who should make treatment decisions. The issues involved in the decision to withhold treatment from infants with spina bifida are complicated by the fact that infants who are not treated may continue to live and may suffer from more serious impairments than they would have had treatment been initially provided. Medical writers have also voiced concern over the kind of life these infants are being saved to face. Many children undergo countless operations and will go through life with severe physical handicaps.

It is essential to examine the issues raised in the medical debate regarding the treatment of spina bifida (and to a lesser extent that of Down's Syndrome) infants since they illustrate many of the difficult medical (clinical and prognostic) and ethical issues which arise within neonatal medicine and since much of the legal and ethical analysis on selective nontreatment has in turn focused on these conditions.

One commentator has criticized (perhaps unfairly) the concentration of legal and ethical writers on these two conditions since they account for but a small proportion of the difficult cases found in neonatal units: 145

> The law and ethics relative to the care of newborns are unexplored territory ... The problem with ethics and law in neonatology is that lawyers and philosophers have been looking at the peaks and have very little awareness of the crevices into which one can easily fall ... The legal and philosophical discussions relative to neonatology are almost exclusively devoted to these two

> kinds of cases [Down's Syndrome and spina bifida] ... Because there is no mention of the prominent problem, the legal analysis of neonatology misses the point ... The dominant problem in the newborn nursery is prematurity.

Two reasons may account for this deficiency. First, the cases which have been brought before the courts have commonly been concerned with requests for orders to operate on Down's Syndrome infants when parents have refused their consent. Another reason is that there has been no comparable 'debate' in the medical literature regarding selective non-treatment of premature (and low birth weight) infants. Indeed, one physician has commented that, "[t]he pediatric literature contains substantial information on the frequency of treatment/nontreatment in only one condition: spina bifida cystica."[146] Thus, it is not surprising that to a large extent the legal and ethical literature has failed to address the issues raised by these other types of cases.

Nevertheless, the medical issues arising in cases of spina bifida are similar to those arising in treating extremely premature and low birth weight infants. Both spina bifida and extreme prematurity may be lethal or may leave the survivors with a variety of physical and/or neurological deficits. However, while physicians can be certain that the infant with spina bifida will suffer from some degree of impairment, there is less certainty of this in the case of premature infants.

(c) The Medical Debate Over the Treatment of Spina Bifida

Before the mid-1950's most infants born with spina bifida died at birth or during infancy. The few who did survive were the less serious cases and suffered from various degrees of handicap.

Surgeons attempted to operate on selective cases of spina bifida during the 1940's. By this time they were able to close the spinal lesion but the operation generally offered little hope of success since there was no treatment available for the associated hydrocephalus. Cerebrospinal fluid which would have leaked out of the wound accumulated in the brain, causing the hydrocephalus and resultant brain damage. Thus infants with milder forms of spina bifida who did not have "significant" hydrocephalus were selected for treatment during this period while those suffering more severe forms were left untreated and allowed to die.

A dramatic turnaround in the treatment of spina bifida occurred with the development of a new shunt system which made it possible to treat the hydrocephalus which occurs in 80% of the cases of myelomeningocele. [147] Because hydrocephalus was a major cause of the morbidity and mortality in infants with spina bifida it became possible to treat thousands of infants who would have previously died soon after birth. John Lorber, a pediatrician specializing in the treatment of children with spina bifida, commented on the effect the discovery had on the treatment of children with the condition: [148]

> It is easy to see that a new technique that makes it possible for the child's head to grow at a normal rate and allows him a chance of developing with normal intelligence could lead to uncritical enthusiasm to treat all infants with myelomeningocele, irrespective of the severity of their condition at birth.

As a result of the discovery, Lorber and his colleagues adopted a policy of vigorous treatment of all infants with spina bifida as soon as possible after birth. This policy gradually spread from the Sheffield unit with which Lorber was associated and became the preferred medical practice throughout the world, although some units and physicians refused to follow the trend and continued to practice some form of selective treatment. [149]

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Several years later, Lorber assessed the results of the policy of universal active treatment at Sheffield. They were both disturbing and disappointing. Of 848 infants with myelomeningocele who had been treated from the day of their birth, only half survived. Three quarters of the deaths had occurred during the first year with the remaining deaths occurring in later years. The survivors who remained were between four and fourteen years of age and continued to die at the rate of 2% a year of chronic and progressive kidney disease and complications with their shunts. Lorber pointed out that it was much more difficult for parents to lose their children after several years of care and numerous operations than it would have been had the child died shortly after birth.

He then turned his attention to the quality of life of the remaining survivors. Of the 424 children who survived, only six had no handicap. Seventy-three (17.2%) had moderate handicaps ("moderate ... in a spina bifida context") while 345 (81.4%) had severe physical handicaps. 150

These results caused Lorber to reassess his views on universal vigorous treatment of all spina bifida patients. He concluded that the massive effort had caused a great deal of pain and suffering for children and their families and urged that the treatment be given to those infants who would most likely benefit from it, rather than attempting to keep children alive who would be severely handicapped.[151]

Not all members of the Sheffield group agreed with Lorber's conclusions. Dr. Robert Zachary, a pediatric surgeon and Lorber's colleague, vigorously opposed a selection policy. Despite Zachary's belief that Lorber's proposed policy of selection was unethical, the Sheffield group decided to initiate a selection policy. Within a short period of time articles began appearing in medical journals by other groups who also advocated selective treatment.[152]

Although selection policies were not universally accepted, the focus of the debate on the treatment of spina bifida shifted from the discussion of whether selection policies should be implemented to a consideration of the criteria that should be used for selection, management of those selected for nontreatment, and who should make these decisions.

The views of Lorber, Zachary and two other physicians with respect to these issues will be examined in the following section.

1. John Lorber

(i) Selection Criteria

"The main object of selection", according to Lorber, "is not to avoid treating those who would die early in spite of treatment, but to avoid treating those who would survive with severe handicaps."[153] By using the prognostic clinical criteria he developed, he argued that it was possible to make a determination on the first day of life about the quality of life an infant was likely to have, although he admitted he could only predict with certainty "the minimum degree of future handicap" in an infant and not the "maximum degree of disability" the child might ultimately suffer.

Lorber designed his criteria to ensure that infants who would suffer only moderate handicaps would not be denied treatment. Moderate physical handicaps in cases of spina bifida involved children who[154]

> are incontinent, or have an ileal loop diversion, but who do not have chronic urinary tract infection or hydronephrosis; if they are able to walk without the aid of calipers, though they may limp, waddle or need surgical boots; if they have analgesia of their legs or perineum but without chronic ulceration or abscess; if they have a hydrocephalus which either required no shunt therapy or hydrocephalus well controlled with a shunt.

Children with severe handicaps under Lorber's classification scheme had handicaps in a more severe form than those above including: [155]

> incontinence with pyelonephritis or hydronephrosis, renal stones or hypertension; paraplegia requiring calipers, crutches or wheelchairs for locomotion; kyphosis or scoliosis; repeated fractures or unreduced, dislocated joints; hydrocephalus under precarious control; blindness, fits or other less common defects.

Although Lorber's initial selection for treatment/non-treatment was made at birth, he argued that the physician had an obligation to reconsider his initial decision at every stage of the child's treatment keeping in mind the likely future quality of the child's life. Thus, subsequent active treatment would be withheld from infants who [156]

> _after_ closure develop meningitis or venticulitis and who already have serious neurological handicap and hydrocephalus, _or later_, if any life-threatening episode occurs in a child who is severely handicapped by gross mental and neurological defects.

Lorber initially suggested four adverse prognostic criteria (later expanded to six) which physicians could use in selecting infants for non-treatment. Any child who suffered at birth from any one or a combination of these physical conditions would suffer severe physical handicaps if he survived and he recommended no treatment be given if any of these adverse criteria were present:[157]

1. A large thoraco-lumbar or thoraco-lumbo-sacral lesion;
2. Severe paraplegia with no innervation below the L3 segment;
3. Kyphosis or scoliosis clinically evident at birth;
4. Gross hydrocephalus, as shown by a head circumference exceeding the 90th percentile by at least 2 cm;
5. Other gross congenital defects, for example, congenital heart disease; and
6. Severe cerebral birth injury or intercranial hemorrhage.

In addition to medical criteria, social criteria were important considerations in making treatment decisions since the infant's environment could ensure a very poor prognosis and thus would constitute a further reason against treatment: [158]

> The worst affected children are those who are illegitimate and others who were immediately abandoned by their families. They live in institutions, retarded and permanently bedridden. Their chances in life are so unfavourable that the criteria for active treatment should be even stricter.

Other social factors which Lorber considered in justifying a policy of selection were the tremendous financial costs entailed in providing care for such children and more importantly, the "disastrous effects" a seriously handicapped child could have on a family.

(ii) Management of Infants Selected for Non-Treatment

Lorber's objective with respect to the infants selected for nontreatment was to ensure their early and painless deaths. To achieve this end, he prescribed a strict regimen of nontreatment, stating: [159]

> It is imperative that non-treatment should really be non-treatment, not just no operation. Nothing should be done to prolong life; no incubators; no

> tube feeding; no antibiotic drugs and most certainly no resuscitation. It is wrong to carry out palliative shunt operations to make management easier. Unoperated hydrocephalus is one of the most important causes of early death ... Half-treatment leads to the most disastrous results. One should either offer total treatment or none at all, other than normal nursing care. The infant should be looked after with gentleness and fed on demand. Analgesics, sedatives or anti-convulsants should be used to ensure his comfort. (underline added).

Lorber described the result of the first 21 months of selective nontreatment at Sheffield. During that period thirty-seven infants with spina bifida were admitted. Twenty-five of these infants were not treated since they were found to fulfill one or more of Lorber's adverse criteria, and were thus expected to have a poor prognosis for a good quality of life. All twenty-five infants were dead within nine months. Of the twelve who had been treated only one had died while one child was severely handicapped.[160] Since all of the untreated infants had died Lorber believed that this should dispel the fears of those who worried that untreated infants might survive with even greater handicaps than they would have had if they had been treated initially. Furthermore, he argued, even if some untreated infants did survive, if his criteria for selection had been carefully followed those infants would not be any worse off than if they had been treated from the start. He wrote:[161]

> They already have gross paralysis, they already have no sphincter control and they already have hydrocephalus. Their spinal lesions will epithelialise. As the spinal lesion has not closed, their hydrocephalus is less likely to be less rapidly progressive or may arrest spontaneously.

Although he believed these cases would be rare if his methods were scrupulously followed he was willing to initiate aggressive treatment if an infant had survived for at least six months and appeared to have good prospects for continued survival.

On the basis of the results achieved following the implementation of his policy of selection, Lorber concluded that selection, while not a good solution to the problem, offered the least bad solution to an insoluble problem.

While Lorber admitted that active euthanasia might be the most humane way of dealing with some of the severe cases he did not treat, he opposed its being legalized since he believed that such a policy could be an extremely dangerous weapon in the hands of unscrupulous individuals.[162]

(iii) Who Should Decide?

Lorber believed that parents' wishes had to be taken into account but the decision to be made was the doctor's duty. Since the decision was based on technical criteria an "expert" had to make the decision. Parents, in Lorber's view, would rarely be sufficiently informed, were under emotional strain and might later feel guilt if they had to make a choice. In any event, he commented that once parents had heard his explanation as to why their child should not be actively treated, no parent ever pressured him to operate nor did any parents ever request second opinions.[163]

(iv) Criticism of Lorber's Criteria

Other centres and physicians who instituted policies of selection in the treatment of infants with spina bifida were critical of Lorber's emphasis on severe physical handicaps as a basis for selection while ignoring the issue of mental handicaps as a determinant of quality of life.

In the United States, Shurtleff et al presented their findings on 371 patients with myelodysplasia, which included 88 patients who had been selected for non-treatment. The criteria for Shurtleff's group differed from Lorber's in that aggressive treatment was recommended for any infant regardless of the level of lesion if a good intellectual prognosis was predicted.[164]

Lorber admitted that using his criteria would mean that some children with normal intelligence would be excluded from treatment and would die. However, he argued that predictions of severe physical handicaps were a sufficient basis for selection since[165]

> ... it is my experience as it is that of psychologists, social workers, teachers and parents that those young people who are severely handicapped by multi-system defects suffer far more if they have normal intelligence than if they are retarded. Only the intelligent realize fully what they have been through, what they have missed and will miss. Only the intelligent will worry about the frustrations of employment, loneliness, lack of opportunity and of normal family life. Only they will worry about their future and who will look after them when their parents are too old or are no longer alive.

2. John Freeman

(i) Selection Criteria

John Freeman, a Baltimore pediatrician, criticized Lorber's criteria of selection although he agreed that not all severely defective infants should be treated. However, he was more skeptical about both the ability and the right of physicians to assess an infant's potential quality of life since he maintained that a child who is born with a disability or handicap has a far different perception of his quality of life than does an adult who is suddenly disabled or handicapped. Freeman submitted that other studies of children with spina bifida showed a much brighter outlook for these infants than Lorber's studies indicated, and he queried whether Lorber's treatment decisions were based upon his own projections about the future quality of their lives, which he argued was not a valid basis for making such decisions. 166

In Freeman's view, the decisionmaker should consider the following factors before making a decision. He should [167]

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> be familiar with the consequences of each alternative with regard to treatment, he must know the prognosis for ambulation and intellectual outlook for the individual child. He must know the facilities and the quality of future care for the infant and the community's ability to provide physical and educational support for the child. He must know the monetary cost of the disease and the family's ability to cope with this cost, or the community's ability to assume it. He must know the parent's desires and their physical and emotional capabilities to handle the physically handicapped child.

He continued: [168]

> Those who make the decision must also know the prognosis for the child who is not treated. They must be aware that many untreated children do not die quickly; some do not die at all. Who is to assume responsibility for the untreated child, for his care, and the expenses thereto?

A consideration of these factors led Freeman to provide treatment in 90% of the cases he dealt with, in contrast to the 25% Lorber treated, a fact which troubled him. He wrote: [169]

> Were a specific child to be brought to Sheffield, he would probably go untreated. If brought to Baltimore, he would be treated. This to me is very disturbing. Which approach is correct? Should a child's life be determined by the accident of the location of his birth or by the pattern of medical referral? Isn't that itself unethical?

(ii) Management of Infants Selected For Non-Treatment

Freeman's central dispute with Lorber concerned the fate of those infants who are selected for nontreatment. He noted that many untreated infants do not die quickly but linger for months or years. More importantly, they could linger on in a worsened condition than if they had been given early aggressive treatment.[170]

He suggested that, in cases where it is clear that death is in the infant's best interest, the most humane course of action would be to directly terminate the infant's life.[171]

However, since active euthanasia is illegal, but passive euthanasia may be inhumane, Freeman concluded, "in an ambivalent fashion, ... that virtually every child should be given optimal vigorous therapy."[172] Having stated this conclusion, he then described a rare case in which he recommended nontreatment. The child would have been a paraplegic with severe multiple anomalies. Freeman considered both harm to the child in addition to familial considerations (young couple, capable of having more children) in making the decision. The child was fed and given "ordinary" care and died within 3 weeks but Freeman emphasized that if the child had survived, he would have reluctantly instituted total, vigorous treatment since partial treatment would result in the worst possible outcome.[173]

(iii) Who Should Decide?

Freeman argued that parents were emotionally incapable of making reasoned treatment decisions for their infants during the first hours and days after birth until they got over their initial feelings of "shock". Thus, when possible he suggested that decisions be deferred for a few days or weeks.[174]

However, Freeman saw the primary decisionmaker as the physician, since he believed that he or she was "[t]he only person capable of truly understanding the consequences of [the] decision."[175]

3. Robert B. Zachary

(i) Selection Criteria

Prior to Lorber's publication of his selection criteria, his colleague, Robert Zachary, a pediatric surgeon, published an article entitled, "Ethical and

Social Aspects of Treatment of Spina Bifida", in which he argued that there are three possible methods of dealing with infants with spina bifida: They should be killed; or encouraged to die by withholding food or medical treatment; or encouraged to live. He rejected the first option as contrary to widely held religious and moral beliefs and claimed that the second option was no better, stating:[176]

> To leave a child without food is to kill it as deliberately and directly as if one was cutting its throat. Even the prescribing of antibiotics for infection, such as pneumonia, must now be considered as ordinary care of patients.

This left the third alternative, namely, that these infants should be encouraged to live. Given this premise, Zachary maintained that the issue therefore, was what method of management or treatment would give these children the "best chance to live" and secondly, would minimize their handicaps.

Zachary pointed out that it is commonly but erroneously assumed that the purpose of performing early surgical closure on an infant born with spina bifida is saving the infant's life. He explained that, in fact, many infants "with myelomeningocele survive without any operation at all on the back, and some die as a direct result of operation when they might otherwise have survived." [177] The surgery is therefore performed in order to preserve movement in the infant's lower extremities and to remove the swelling to enhance the infant's quality of life.

However, Zachary did not advocate surgery for all infants with spina bifida. His criteria for selection involved placing the infants in one of three categories. Surgery was withheld from infants in the first category, as these infants were judged likely to die within a few days or weeks and the surgery was deemed to be futile. Infants in Zachary's second category were not dying, but their lesions were unsuitable for surgical closure, as "there would be a risk of wound breakdown, which would be far worse than no operation at all." [178] Therefore, no surgical treatment was given to infants in this category. Zachary recommended surgery for infants in the third category since these infants were likely to survive and their back wounds were suitable for closure. Within this group, Zachary advocated immediate surgery for infants with some active leg movement, or muscle activity and surgery within 48 hours for infants who were completely paralyzed. [179]

He rejected Lorber's assumption that many of these infants should be allowed to die because of the potential unhappy lives that await them, stating: 180

> It is sometimes said that these infants should be left to die (or encouraged to die), mainly because their lives will be nothing but misery and unhappiness due to their disability. Yet extreme disability is not synonymous with unhappiness, and we are only at the beginning of finding ways of developing the capabilities of these patients to the maximum either in work or recreation.

(ii) Management of Infants Selected For Non-Treatment

Zachary, like Freeman, stressed the fact that some infants selected for nontreatment do not die. He seriously questioned Lorber's (and other advocates of selective nontreatment) studies which claimed a nearly 100% mortality rate in the infants they chose not to treat, claiming: 181

> My own personal experience of the survival of these infants differs so greatly from that in other series (some with a mortality of 100%) that one is entitled to wonder whether all these infants are receiving the ordinary standard of baby care that one would expect in the 1970's or whether they are receiving drugs, for which there is

> no therapeutic indication, in order to make them sleepy so they will demand no feed.

In this regard, Zachary cited the practice of some physicians who administer "eight times the sedative dose of chloral hydrate recommended in the most recent volume of Nelson's Pediatrics" and claimed that it was "[n]o wonder that these infants demand no feed" [182] and expire within days or a few weeks. Such practices, were in his view, clearly unethical and he queried whether they were not illegal as well.

He stated that he would never "under any circumstances" administer drugs to cause the death of a child nor would he withhold all treatment as Lorber suggested. Instead, he offered infants who had been operated on, as well as those who were not, "further operations on the hydrocephalus or the renal tract or orthopaedic operations [in order] to improve the function or prevent its deterioration." [183]

(iii) Who Should Decide?

Zachary maintained that the "final decision rests with the parents" and he sought to "avoid any comment that would leave them with a longstanding feeling of guilt", even where they refused their consent to treat although he recommended treatment.

4. Richard H. Gross

(i) Selection Criteria

Another approach to the management of children born with myelomeningocele was published in the October, 1983 issue of *Pediatrics*.[184] Gross and his colleagues developed a system of selective nontreatment for infants with spina bifida which had been used at the University of Oklahoma Health Sciences Center over a five year period. Sixty-nine infants were evaluated, with vigorous treatment being recommended for 36 babies (52%) and supportive care only for 33 babies (48%). Of these 33 infants, 5 were given initial treatment at the parents' request. Two of these infants died but the remaining three were "alive and well". Three of the remaining 28 babies selected for nontreatment were subsequently treated and continued to live, while one infant moved and was lost to follow-up. Twenty-four infants were given supportive care only, all of whom died (mean of 37 days).

The authors stated they had "no specific criteria for treatment" but indicated that "factors considered significant by Shurtleff et al and to a lesser extent considered significant by Lorber are reviewed,". 185 Other nonmedical factors, including the infant's family circumstances were also considered and they concluded: 186

> With the perspective gleaned from the long-term care of these children, even without hard 'criteria', valuable and pertinent information can be gathered within a few days after birth to make a reasoned decision - a decision that considers the perspective of both baby and family.

(ii) Management of Infants Selected For Nontreatment

For those infants who were selected for nontreatment, no antibiotics were given nor was sedation prescribed in order to refute earlier allegations made by Zachary "that babies selected for only supportive care do not die spontaneously". 187

(iii) Who Should Decide?

Gross and his colleagues supported the philosophy that parents should make treatment decisions for their children after extensive consultations with the members of the health care team. Contrary to Magnet and Kluge's findings, they were willing to provide aggressive treatment if the family so wished, although their own recommendation was against it "unless the operative risk [was] considered a direct threat to the infant's life."[188]

(d) Conclusion

The foregoing views represent but a few selected opinions about the management of infants with spina bifida. Yet, they serve to illustrate the diversity of medical opinion that exists with regard to the treatment of one relatively common, and complex condition afflicting newborn infants.

Although there is agreement that some cases of spina bifida are so severe that nontreatment is warranted, there is disagreement over the criteria and the reasons justifying nontreatment.

Zachary is only willing to exclude from treatment those infants whose conditions are fatal or whose lesions are untreatable. Freeman agrees with Zachary but argues that in such cases, euthanasia is preferable to "letting" the infants die. Lorber (and Gross), on the other hand, are willing to select a much larger number of infants for nontreatment based upon their projections of an infant's probable quality of life. For Lorber, severe physical impairment precludes the ability of a child to achieve a minimal quality of life, while other physicians, such as Shurtleff, agree with Lorber's principles of selection, but argue that the predicted degree of mental handicap is the key component determining an infant's potential quality of life. Both Freeman and Zachary doubt doctors' (or anyone else's) ability to predict an infant's future quality of life, and Zachary argues that, even if it were possible, the doctor's duty is to try to minimize the infant's handicaps and to improve the quality of the infant's life.

A further justification for nontreatment in Lorber's view are the disastrous effects of such children on their families. Freeman disputes Lorber's claims and both he and Zachary submit that we should not do away with such children, rather more should be done to help their families.

Physicians also disagree about the management of infants selected for nontreatment. Lorber maintains that untreated infants should not be given antibiotics to combat infections and should be sedated and fed only on demand thereby accelerating the infants' deaths. Zachary considers the administration of antibiotics to be "ordinary" and therefore required care for these infants. Freeman, Zachary and Gross all oppose the administration of sedatives to hasten death, although for different reasons. Freeman believes that doing so is illegal but would be willing to do so if the law were changed, while Zachary contends that the practice is morally indistinguisable from direct killing which he considers to be unethical as well as illegal. Gross and his colleagues offer no ethical justification for withholding sedation rather, they do so, in order to counter claims that nonsedated infants do not die quickly.

With respect to the procedural question - who should decide, there is also disagreement. For Lorber, the decision is principally the physician's (although he consults with the family) since the decision is based upon technical criteria. Freeman also believes the physician is better equipped to make the decision because of his or her greater objectivity in comparison to the parent's emotional involvement. Zachary and Gross are in favor of parental autonomy in making the decisions and will generally treat, if that is the parent's wish, even though they disagree.

To nonmedical observers, it is apparent that decisionmaking behind the closed doors of neonatal units may lead to widely different numbers and groups of infants being selected for nontreatment. Ethicists and lawyers who debate these issues argue that such divergent practices cannot all be ethical and some are probably illegal. The next Chapter of this paper will therefore examine the current law regarding the provision of medical treatment to defective infants.

CHAPTER 1 ENDNOTES

1. John Lorber, "Ethical Problems in the Management of Myelomengocele and Hydrocephalus," (1975) 10 J Roy Coll Physicians, 47. Peter B. Budetti and Peggy McManus, "Assessing the Effectiveness of Neonatal Intensive Care," (1982) 20 Med Care, 1027.

2. Iatrogenic problems are caused as a result of the treatment itself. For example, in the late 1940's and early 1950's premature infants were administered massive doses of oxygen to assist their breathing until it was discovered that high dosages of oxygen caused blindness, a condition known as retrolental fibroplasia (RLF) or retinopathy of prematurity.

3. Albert R. Jonsen, "Ethics, the Law and the Treatment of Seriously Ill Newborns," in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, eds. A. Edward Doudra and J. Douglas Peters (Ann Arbor, Michigan AUPHA PRESS, 1982), p.p. 239-39.

4. Robert Usher, "Extreme Prematurity," in Neonatology: Pathophysiology and Management of the Newborn, ed. Gordon B. Avery, 3rd ed. (Philadelphia, Pennsylvania: J.B. Lippincott Company), p. 264. Usher writes that "only 0.87% of live births occur before 31 weeks "yet this gestational age group now accounts for 84% of neonatal deaths among infants of all ages".

5. Betty Wolder Levin, "Consensus and Controversy in the Treatment of Catastrophically Ill Newborns: Report of a Survey," in Which Babies Shall Live?, eds. Thomas A. Murray and Arthur L. Caplan (Clifton, N/J.: Humana Press, 1985), p.180.

6. Rasa Gustatis and Ernle W.D. Young, A Time to be Born, A Time to Die, (Reading, Mass: Addison-Wesley, 1986), p. 48. The authors explain that only 50% of infants of less than 800 grams make it out of the delivery room, and of those who do only 50% survive. But little is known about their future prospects as it is only since 1982 that enough of them have survived in order to permit any statistical data gathering. See also Budetti and McManus, supra n.1 at 1030. The first controlled clinical trials of CPAP (continuous positive airway pressure) which had been hailed as a breakthrough in the treatment of RDS

(respiratory distress syndrome) were not conducted until several years after CPAP had been widely adopted and the study did not show any "statistically significant improvement in mortality."

7. John A. Robertson, "Dilemma in Danville," (1981) 11 Hastings Cent Rep, 6.

8. Joel E. Frader, "Selecting Neonatal Ethics," (1985) 20 Soc Sci & Med, 1086.

9. Id., at 1086. Although Frader is an American physician similar conditions motivate Canadian doctors according to Joseph Magnet, who claims that Canadian doctors - partly out of the fear of the law tend to overtreat. See "Defective Infants: life-or-death dilemma," Montreal Gazette, August 9, 1986, A1. See also Robert and Peggy Stinson's harrowing account of the overtreatment of their infant son, Andrew, in The Long Dying of Baby Andrew (Boston: Little, Brown and Company, 1983).

10. Raymond S. Duff and A.G.M. Cambell, "Moral and Ethical Dilemmas in the Special Care Nursery," (1973) 289 New Eng J Med, 890. During a 30 month period, (January 1, 1970 - June 30, 1972) the nursery admitted 2,171 infants. Of the 229 deaths which occurred, 43 were related to the withholding of medical treatment.

11. Id., at 894.

12. Anthony Shaw, "Dilemmas of 'Informed Consent' in Children," (1973) 289 New Eng J Med, 885.

13. See for example, Physicians: Graham W. Chance, "The Severely Handicapped Newborn: A Physician's Perspective," (1980) 2 Health Law Can, 34; John M. Freeman, "Is There a Right to Die Quickly," (1972) 80 J Pediatr, 904; John Lorber, "Selective Treatment of Myelomeningocele: To Treat or Not to Treat?," (1974) 53 Pediatr, 307; R.B. Zachary, "Ethical and Social Aspects of Treatment of Spina Bifida," (1968) 2 Lancet, 274. Lawyers: Joseph Eliot Magnet, "Withholding Treatment from Defective Newborns: A Description of Canadian Practices," (1980) 4 Legal Med Q, 271; John A. Robertson, "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," (1975) 27 Stan L Rev, 213; Steven R. Smith, "Life and Death Decisions in the Nursery: Standards and

Procedures For Withholding Lifesaving Treatment From Infants," (1981-82) 27 N.Y. L Sch L Rev, 1125. Ethicists and Philosophers: J.M. Gustafson, "Mongolism, Parental Desires and the Right to Life," (1973) 16 Persp Bio & Med, 529; Eike-Henner W. Kluge, "The Euthanasia of Radically Defective Neonates: Some Statutory Considerations," (1981) 6 Dalhousie L J, 229.

14. Kimball J.P. Sargeant, "Withholding Treatment from Defective Newborns: Substituted Judgement, Informed Consent and the Quinlan Decision," (1978) 13 Gonzaga L Rev, 781.

15. The term "neonatology" was coined by Dr. Alex Schaffer in 1960 during a period of rapidly expanding interest in the body processes of newborn infants, known as neonates. Within obstetrics, new advances resulted in the specialty of maternal-fetal medicine called perinatology. See Gordon B. Avery, "Neonatology: Perspective in the Mid 1980's," in Avery, Neonatology, p.p. 3-5.

16. Alan R. Fleischman, "Caring for Babies in Danger: The Evolution and Current State of Neonatology," in Which Babies Shall Live?, eds. Thomas H. Murray and Arthur L. Caplan (Clifton, N.J.: Humana Press, 1985), p. 15.

17. William H. Tooley and Roderic H. Phibbs, "Neonatal Intensive Care: The State of the Art," in Ethics of Newborn Intensive Care, eds. Albert R. Jonsen and Michael J. Garland (Berkeley, California: Institute of Governmental Studies, 1976), p. 12.

18. Clement A. Smith, "Neonatal Medicine and the Quality of Life: An Historical Perspective," in Ethics of Newborn Intensive Care (Berkeley, California: Institute of Governmental Studies, 1976), p. 33.

19. Supra n.16 at 16-17.

20. Supra n.6 at 36. See also, Usher, supra n.4 at 271-72.

21. Usher, supra n.4 at 276-78. See also, Edward F. Bell and William Oh, "Fluid and Electrolyte Management," in Avery, Neonatology, p.p. 789-90; Gordon B. Avery and Anne B. Fletcher, "Nutrition," in Avery,, Neonatology, p.p. 1204-12.

22. Usher, supra n.4 at 286; Joan E. Hodgman, "Chronic Lung Disease," in Avery, Neonatology, p.p. 446-59.

23. Avery and Fletcher, supra n.21 at 1211-12.

24. Supra n.6 at 42.

25. Supra n.15 at 5.

26. Id., at 5.

27. Peter B. Budetti and Peggy McManus, "Assessing the Effectiveness of Neonatal Intensive Care," (1982) 20 Medical Care, 1027.

28. Paul R. Swyer, "The Organization of Perinatal Care With Particular Reference to the Newborn," in Avery, Neonatology, p. 18.

29. Supra n.4 at 265.

30. Jack Hadley, More Care, Better Health? (Washington, D.C.: Urban Institute Press, 1982), p.p. 33-34. Reprinted in Earl Shelp, Born to Die? Deciding the Fate of Critically Ill Newborns (New York: The Free Press, 1986), p. 86.

31. For example, in Alberta, in 1986 congenital anomalies accounted for 20% of all infant deaths (infants between birth and 1 year) and 27% of all neonatal deaths (birth - 28 days). See Alberta, Vital Statistics Annual Review, 1986. Table 12 - Infant Deaths, Cause By Sex and Age, 1986.

32. Murray Feingold, "Congenital Malformations," in Avery, Neonatology, p. 1033.

33. President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (Washington, D.C: U.S. Governmental Printing Office, 1983), p. 202.

34. Marie C. McCormick, "The Contribution of Low Birth Weight to Infant Mortality and Childhood Morbidity," (1985) 312 New Eng J. Med, 86.

35. Supra n.27 at 19.

36. Supra n.15 at 10.

37. Id., at 10.

38. Fred M. Frohock, Special Care: Medical Decisions at the Beginning of Life (Chicago: University of Chicago Press, 1986), p. 155. Frohock contends that "assigning a price tag to life seems to be a case of combining incommensurate values" and that "cost constraints are difficult to justify on moral grounds."

39. Martha J. Kramer, "Ethical Issues in Neonatal Intensive Care: An Economic Perspective," in Ethics of Newborn Intensive Care, eds. Albert R. Jonsen and Michael A. Garland (Berkeley, California: Institute of Governmental Studies, 1976), p.p. 77-78.

40. Michael H. Boyle et al., "Economic Evaluation of Neonatal Intensive Care of Very-Low-Birth-Weight Infants," (1983) 308 New Eng J Med, 1330.

41. Id., at 1334.

42. Donna Jean Walker et al., "Cost-Benefit Analysis of Neonatal Intensive Care for Infants Weighing Less Than 1,000 Grams at Birth," (1984) 74 Pediatr 20.

43. Id., at 20.

44. Bernard M. Dickens, Comment on Dawson Case, (1984) 62 Can Bar Rev, 205.

45. Joseph E. Magnet, "Withholding Treatment From Defective Newborns: A Description of Canadian Practices," (1980) 4 L Med Q, 271.

46. Paul R. Swyer, "Organization of Neonatal Units," in The Intensive Care of the Newly Born: Physiological Principles and Practices, ed. Paul R. Swyer, Monographs in Pediatrics, vol. 6 (Basel, Switzerland: Karger, 1975) p. 97.

47. Supra n.15 at 5.

48. Joseph Eliot Magnet and Eike-Henner W. Kluge, Withholding Treatment from Defective Newborn Children (Cowansville, Quebec: Brown Legal Publications Inc., 1985), p. 8, f.n. 3. In Alberta, fetal-obstetric care is integrated with neonatal care at the University Hospital in Edmonton and at the Foothills Hospital [as well as the Peter Lougheed Centre] in Calgary.

49. *Supra* n.46 at 99.

50. *Supra* n.48 at 9.

51. *Supra* n.46 at 96. Swyer comments that one perinatologist- pediatrician can look after 100 intensive care and 150 intermediate care patients annually, having regard to his other responsibilities, including teaching and research.

52. Robert F. Weir, *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine* (New York and Oxford: Oxford University Press, 1984), p. 32.

53. *Supra* n.46 at 96.

54. *Supra* n.48 at 19.

55. *Supra* n.46 at 99.

56. *Supra* n.6 at 59.

57. Mitzi L. Duxbury, "The Role of the Nurse in Neonatology," In Avery, *Neonatology*, p.p. 57-59.

58. *Supra* n.46 at 96.

59. *Supra* n.52 at 37-38.

60. United States: (1) The "Baby Doe" case, (2) Baby Jane Doe case. Britain: (1) The "Arthur" case, (2) *In re B*. Australia: The Derkacs case.

61. Candace Taschuk, an infant born at the University Hospital in Edmonton was given an overdose of morphine on the instructions of Dr. M. Gal.

62. Fred Frohock, a professor of political science at Syracruse University spent four months as a participant observer in a neonatal unit in a northwestern state, and wrote a book describing his experience entitled, *Special Care: Medical Decisions at the Beginning of Life* (Chicago: University of Chicago Press, 1986). Rosa Gustatis and Ernle W.D. Young, a journalist and ethicist spent eighteen months observing decisionmaking practices at the Stanford University Medical Center Intensive Care Nursery. Their book describing their experiences is entitled, *A Time to be Born, A Time to Die* (Reading, Mass: Addison-Wesley, 1986); Jeanne Horley Guillemin

and Linda Lytle Holmstrom, Mixed Blessings (New York and Oxford: Oxford University Press, 1986). The authors spent six months observing neonatal care at a large pediatric hospital in the eastern United States, in addition to visiting and interviewing staffs at 14 Level III units across the United States. Further visits and interviews were conducted at comparable nurseries in England, the Netherlands, East and West Germany, France and Brazil.

63. United States: Diana Crane, The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients (New York: Russel Sage Foundation, 1975); Albert R. Jonsen et al., "Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal," (1975) 55 Pediatr, 756; Betty Wolder Levin, "Consensus and Controversy in the Treatment of Catastrophically Ill Newborns: Report of a Survey," in Which Babies Shall Live?, eds. Thomas H. Murray and Arthur L. Caplan (Clifton, N.J.: Humana Press, 1985). Anthony Shaw, Judson G. Randolph, and Barbara Manard, "Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons," (1977) 60 Pediatr, 588; I.D. Todres et al., "Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns," (1977) 60 Pediatr, 197.

Canada: Joseph Eliot Magnet and Eike-Henner W. Kluge, Withholding Treatment from Defective Newborn Children (Cowansville, Quebec: Brown Legal Publications Inc., 1985).

Australia: Peter Singer, Helga Kuhse and Cora Singer, "The Treatment of Newborn Infants with Major Handicaps," (1983) 2 Med J Aust, 274.

64. David J. Roy, ed. Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children. Proceedings of a Symposium held on November 18, 1976 by the Center for Bioethics, Clinical Research Institute of Montreal (Montreal: Eden Press, 1978); Chester A. Swinyard ed. Decisionmaking and the Defective Newborn. Proceedings at a conference at spina bifida (Springfield, Ill.: Charles C. Thomas, 1977).

65. Paul and Marlys Bridge, "The Brief Life and Death of Christopher Bridge," (1981) 11 Hastings Cent Rep, 17. The Bridges were critical of neonatal decisions

about the withdrawal of treatment being made behind closed doors and with their inability to obtain complete information about their son's medical condition; Robert and Peggy Stinson, "On the Death of a Baby," Atlantic Monthly, July, 1979, reprinted in (1981) 7 J Med Ethics, 5 and a longer account of their son's treatment was published as a book entitled, The Long Dying of Baby Andrew (Boston: Little Brown, 1983). The Stinsons felt completely excluded from the decisionmaking process and watched helplessly over a period of several months as a series of painful treatments were given which increased their premature son's suffering until his eventual death.

66. President's Commission, supra n.33 at 208. See also Frader, supra n.8 at 1086.

67. Crane, supra n.63 at 25.

68. Id., at 25.

69. Id., at 50-51.

70. Id., at 50.

71. Id., at 98.

72. Id., at 201.

73. Supra n.48 at 8-44.

74. John Douglas, "Report on Euthanasia Called Misguided," Globe and Mail, June 16, 1986, p.A16.

75. Id., at 16.

76. Supra n.63.

77. A.G.M. Cambell, "Which Infants Should Not Receive Interim Care?," (1982) 57 Arch Dis Childh, 569; A.G.M. Cambell and R.S. Duff, "Deciding the Care of Severely Malformed or Dying Infants," (1979) 5 J Med Ethics, 65; Raymond S. Duff and A.G.M. Cambell, "Moral and Ethical Dilemmas in the Special Care Nursery," (1973) 289 New Eng J Med, 890; Raymond S. Duff, "Counselling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'," (1981) 67 Pediatr, 315; John Lorber, "Selective Treatment of Myelomeningocele: To

Treat or Not to Treat?" (1974) 53 Pediatr, 307; John Lorber, "Ethical Problems in the Management of Myelomeningocele and Hydrocephalus," (1975) 10 J Roy Coll Physcns, 47; John Lorber, "The Doctor's Duty to Patients and Parents in Profoundly Handicapping Conditions," in Roy, Medical Wisdom and Ethics, p. 21; A. Shaw, "Doctor, Do We Have a Choice?" New York Times Magazine, January 30, 1972, p. 44.

78. Sarah Scott, "Defective Infants: Life-or-Death Dilemmas," Montreal Gazette, August 9, 1986, p. A4.

79. Crane, supra n.63 at 72.

80. Id., at 200.

81. Singer, supra n.63 at 275.

82. Jonsen, supra 63 at 767.

83. Id., at 767.

84. Supra n.48 at 35. See also Frohock, supra n.38 at 49 discusses this practice. It is also mentioned by (former) Medical Examiner, Dr. Jennifer Rice, in her report on the deaths which occurred in the University Hospital NICU from January 1, 1982 - February 29, 1983. A review of the hospital files of infants who died in the NICU revealed that morphia may be used in the terminal phases of a baby's illness. Morphia was administered to four infants in this manner during that period.

85. Canadian Pediatric Society's Bioethics Committee's Policy Statement on Defective Infants (June, 1983).

86. Supra n.48 at 35.

87. Supra n.38 at 49. Interview with Dr. "Bill Wade" (name changed to protect identity).

88. Information/data to develop this report has been provided by the Office of the Chief Medical Examiner, Alberta Attorney General, Calgary, Alberta, Canada, Police Report - Continuation Sheet, p.14.

89. Report of the Fatality Inquiry, p.5.

90. Police Report - Continuation Sheet, p.14.

91. Dr. Shiff's remarks were quoted in Alberta Report, August 15, 1983, p.30.

92. Testimony of Mr. Simon Renouf reported in the Edmonton Journal, July 7, 1983, p.A12.

93. The supervising nurse in this case was fired by the hospital while the nurse who gave the morphine quit and was also suspended by the Alberta Registered Nurses Association for one year. Calgary Herald, July 9, 1986, p.A5.

94. Report of the Fatality Inquiry, p.8.

95. The Perinatal Mortality Review Committee is responsible for the establishment and maintenance of standards. The particular hospital's standards are compared with national and international standards and are reviewed by (1) the Royal College of Physicians and Surgeons and (2) the Canadian Council on Hospital Accreditation. Personal Interview with Peter E. Swerhone, Executive Director, Northern Alberta Children's Hospital, Edmonton, Alberta, July 27, 1987.

96. Supra n.48 at 13.

97. Id., at 12.

98. Supra n.38 at 6.

99. Id., at 6.

100. Id., at 10. However, Magnet and Kluge found that all units in Canada (save one) report utilization beyond design capacity. Supra n.48 at 4, f.n. 6.

101. Supra n.48 at 16-17.

102. Supra n.33 at 209. This problem was discussed by Peggy Stinson, supra n.65. It took several hours for her to drive to the hospital where her son was being treated. Mrs. Stinson felt that this made communication with the doctors and nurses more difficult, since she could not get there often and believed that the nurses interpreted this as not caring.

103. Supra n.6 at 12-15, 25.

104. Supra n.65. Both the Bridges and the Stinsons discussed personal clashes with the physicians involved in their children's care.

105. William A. Silverman, "Mismatched Attitudes About Neonatal Death," (1981) 11 Hastings Cent Rep, 12; Rosalyn Benjamin Darling, "Parents, Physicians and Spina Bifida," (1977) 7 Hastings Cent Rep, 10.

106. Supra n.33 at 210.

107. Bridge, supra n.65 at 18.

108. Raymond S. Duff and A.G.M. Cambell, "Moral and Ethical Dilemmas in the Special-Care Nursery," (1973) New Eng J Med, 894. Duff and Cambell argue that "physicians may hold excessive power over decision making by limiting the information made available to parents or families."; Magnet and Kluge, supra n.48 at 29 state that "the flow of medical information is used as a lever to control the decision-making process." A similar conclusion was reached by the President's Commission, supra n.33 at 209. The Commission commented that "parents may be excluded from the decisions entirely or presented with a narrower range of choices than is appropriate."

109. Supra n.38 at 160-61.

110. Supra n.48 at 27.

111. Helen Harrison, "Neonatal Intensive Care: Parent's Role in Ethical Decisionmaking," (1986) 13 Birth, 165.

112. Id., at 174.

113. Supra n.48 at 27, f.n. 29. Magnet and Kluge found in their study that none of the physicians could say what the informed consent doctrine required and that some physicians referred to it as nonsense.

114. Shaw survey, supra n.63 at 593. In a nationwide survey of American pediatric surgeons and pediatricians when asked whether parents can be fully informed to make reasonable decisions within hours or days after the birth of a seriously ill or handicapped child, 25.5% of the surgeons and 32.6% of the pediatricians replied they could not.

115. Supra n.48 at 68.

116. Todres et al., supra n.63 at 198.

117. Shaw, supra n.63 at 590.

118. Supra n.48 at 28. See also Guillemin and Holmstrom, supra n.61 at 121.

119. Crane, supra n.63 at 52.

120. Supra n.38 at 42.

121. Supra n.48 at 30-31.

122. Crane, supra n.63 at 21. Crane found that some physicians (especially young physicians) find themselves incapable of making decisions in difficult cases so that in the end the decision is made for them by events or changes in the patient's condition.

123. Supra n.48 at 19-20.

124. Joan E. Hodgman, "Withholding Treatment From Seriously Ill Newborns: A Neonatologists View," in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, eds. A. Edward Doudra and J. Douglas Peters (Ann Arbor, Michican: AUPHA PRESS, 1982), p.243; Gustatis and Young, supra n.6 at 57; Guillemin and Holmstrom, supra n.62 at 64-66.

125. Levin, supra n.63 at 193.

126. Supra n.48 at 40. See also Shaw, supra n.63 at 593. In Shaw's survey 90.7% of pediatric surgeons and 86.5% of pediatricians marked the potential quality of the infant's life as the major criterion for nontreatment.

127. Supra n.38 at 85. See also A.G.M. Cambell, "Which Infants Should Not Receive Interim Care?" (1982) 57 Arch Dis Childh, 570.

128. Supra n.48 at 24. See also Crane, supra 63 at 46. Crane concluded: "The interviews suggested that the medical standards which are applied to mentally retarded children are different from those which are applied to normal children." In Betty Levin's survey, supra n.63 at 189, Levin asked the respondents (physicians and nurses) to express their opinions about the basis of decisions to withhold treatment. Most indicated severity of intellectual

impairment, followed by amount of prolonged pain and suffering, severity of physical impairment and parent's wishes. However, there was a distinction between neonatologists and nurses about which factor should be the most important consideration. More neonatologists cited the amount of intellectual impairment (45 v. 25%), whereas more neonatal nurses thought the amount of pain and suffering should be the most important factor (28 v. 3%).

129. Levin, supra n.63 at 193.

130. Id., at 193.

131. Supra n.48 at 15. Frohock discussed the standard criteria for resuscitation in the neonatal unit he observed. The majority of physicians in that nursery would not treat infants under 500 grams or 24 weeks gestation unless they continued to breathe spontaneously and maintained a good heart rate, as they beleived that less than 500 gram and 24 weeks gestation babies do not have enough air sacs in their lungs to survive. However, the head neonatologist in the unit did not agree and treated all infants.

132. Crane, supra n.63 at 46. See also President's Commission, supra n.33 at 210.

133. Crane, supra n.63 at 81. See also President's Commission, supra n.33 at 210 and Gustatis and Young, supra n.6 at 171.

134. Supra n.48 at 40; Frohock, supra n.38 at 91. See also Todres, supra n.63 at 200. The willingness of the parent to care for the child was a major consideration in physicians' decisions "to 'Run Slowly' or take 'Heroic Measures.'" (63%). See also Guillemin and Holmstrom, supra n.62 at 139-141.

135. Marital Status: (if parents are married physicians are more likely to treat) Magnet and Kluge, supra n.63 at 21; Crane, supra n.63 at 50; Quality of Family: Magnet and Kluge at 22. Effect of Child on Family: Magnet and Kluge at 22-23; Anthony Shaw, "The Ethics of Proxy Consent," in Decision Making and the Defective Newborn, ed. Chester A. Swinyard (Springfield, Ill: Charles C. Thomas, 1977), p.593; Family Finances: Magnet and Kluge at 23; Crane at 53; Todres, supra n.63 at 200; Ability of parents to have additional children: Magnet and Kluge at 24;

Adequacy of institutional care: Todres at 200. Opportunity to learn, practice, teach new techniques: Crane at 81; Feelings of hospital staff: Todres at 200; Costs to Society: Magnet and Kluge at 23; Crane at 80; Shaw at 593.

136. Supra n.48 at 41.

137. Supra n.6 at 133.

138. Id., at 134. See also Crane, supra n.63 at 40.

139. Supra n.48 at 43. See also Frohock, supra n.38 at 41. But see, Commentary, "The Ethics of Surgery in Newborn Infants," (1969) 8 Clin Pediatr, 251. Individual physicians may decide whether or not to administer antibiotics.

140. Supra n.48 at 34 and 43.

141. Anthony Shaw, "Doctor, Do We Have a Choice?" New York Times Magazine, January 30, 1972, 44; Eugene F. Diamond, "The Deformed Child's Right to Life," in Death, Dying and Euthanasia, eds. Dennis J. Horan and David Mall (Washington, D.C.: University Publications of America, Inc. 1977), p.127. F.M. Guttman, "On Withholding Treatment," (1974) 111 CMAJ, 520. See also D.P. Girvan and C.A. Stephens, "Congenital Intrinsic Duodenal Obstruction," (1974) 9 J Pediatr Surg, 837. The authors conducted a 20 year review of the surgical management of infants with intestinal blockages. Between January, 1952 - December, 1971 among 158 cases, 38 were not surgically corrected, 27 had Down's Syndrome and 11 had other severe anomalies.

142. Another serious neural tube defect is anencephaly, a condition in which an infant is born without a brain or only a rudimentary portion of brain tissue. Anencephalic infants may be stillborn or they may die within the first few hours or days after birth. No treatment is possible. Recently, a Canadian couple donated the heart of their anencephalic infant for transplant to another infant. Although the physicians waited until the infant stopped breathing, the case aroused considerable controversy. Some physicians and ethicists thought it set a dangerous precedent and wondered whether it would open the door to organs being taken from profoundly retarded infants. A national pediatric task force has been

struck by the Canadian Pediatric Society in order to establish guidelines to deal with this issue. *Calgary Herald*, June 29, 1988, p.A1. See also, "Doctors Grapple with Ethics," *Newsweek*, December 28, 1987, p.62.

143. Helga Kuhse and Peter Singer, *Should the Baby Live? The Problem of Handicapped Infants* (Oxford: Oxford University Press, 1985), p.49.

144. Robert F. Weir, *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine* (New York and Oxford: Oxford University Press, 1984), p.43.

145. Albert R. Jonsen, "Ethics, the Law and the Treatment of Seriously Ill Newborns," in *Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients*, eds. A. Edward Doudra and J. Douglas Peters (Ann Arbor, Michigan: AUPHA PRESS, 1982), p.p. 236-37.

146. *Supra* n.143 at 49.

147. *Supra* n.142 at 49.

148. Id., at 49.

149. *Supra* n.143 at 54.

150. *Supra* n.142 at 51.

151. John Lorber, "Results of Treatment of Myelomeningocele: An Analysis of 524 Unselected Cases With Special Reference to Possible Selection for Treatment," (1971) 13 *Devel Med Child Neurol*, 279. It was in this paper that Lorber first suggested a policy of selective nontreatment.

152. G. Keyes Smith and E. Durham Smith, "Selection for Treatment in Spina Bifida Cystica," (1973) 4 *Br Med J*, 189; Cambell and Duff, *supra* n.10 at 890.

153. *Supra* n.142 at 53.

154. John Lorber, "Spina Bifida Cystica" Results of Treatment of 270 Consecutive Cases with Criteria for Selection for the Future," (1972) 47 *Arch Dis Child*, 856.

155. Id., at 856.

156. John Lorber, "Selective Treatment of Myelomeningocele: To Treat or Not to Treat," (1974) 53 Pediatr, 307.

157. Supra n.142 at 53.

158. Supra n.151 at 296.

159. John Lorber, "The Doctor's Duty to Patients and Parents in Profoundly Handicapping Conditions," in Medical Wisdom and Ethics in the Treatment of Severely Defective Newborn and Young Children (Montreal: Eden Press, 1978), p. 21.

160. John Lorber, "Early Results of Selective Treatment of Spina Bifida Cystica," Br Med J, 264. These results were later updated in 1981. See John Lorber and S.A.W. Salfield, "Results of Selective Treatment of Spina Bifida Cystica," (1981) 56 Arch Dis Child, 822. The original 37 babies were included in a series of 120 infants evaluated from 1971-76. Among 71 infants not treated, all died with 90% dying within 6 months.

161. Supra n.142 at 55.

162. Supra n.156 at 308.

163. Supra n.142 at 54.

164. D.B. Shurtleff; P.W. Hayden; J.D. Lowser, et al., "Myelodysplasia: Decision for Death or Disability," (1974) 291 New Eng J Med, 1005. Shurtleff recommended aggressive treatment be undertaken if all of the following criteria were present: (1) Frontal cerebral mantle greater than 1.0 cm or brain mass greater than 60% mean for age; (2) absence of a systemic disorder that could cause hydrocephalus and severe brain malfunction; (3) absence of roentgenographic and neurologic signs of severe brain deformity; (4) absence of noteworthy central nervous system (CNS) bleeding and infection; (5) absence of major malformations that would preclude self-care as an adult; and (6) a family with economic and intellectual resources who lived within reach of an appropriate medical facility, or a commitment by a social agency to provide needed resources such as a foster home or medical care costs.

165. Supra n.142 at 54.

166. John M. Freeman, "Ethics and the Decision Making Process for Defective Children," in Medical Wisdom and Ethics in the Treatment of Severely Defective Children, ed. Dr. David J. Roy (Montreal: Eden Press, 1978), p.34.

167. John M. Freeman, "To Treat or Not to Treat: Ethical Dilemmas of Treating the Infant with a Myelomingocele," (1973) 20 Clin Neurosurg, 141.

168. Id., at 141.

169. Supra n.166 at 28.

170. John M. Freeman, "Is There a Right to Die - Quickly?" (1972) 80 J Pediatr, 904-05. For a critique of Freeman's position see R.E. Cooke, "Whose Suffering?" (1972) 80 Pediatr, 906-07.

171. Id., at 905.

172. Supra n.167 at 143. See also supra n.170 at 904-05.

173. Supra n.167 at 145. See also John M. Freeman, "Short-Sighted Treatment of Myelomeningocele," (1974) 53 Pediatr, 311-313, in which Freeman describes the unfortunate results of a case of selective nontreatment in which the child did not die.

174. Michael Hemphill and John M. Freeman, "Ethical Aspects of Care of the Newborn with Serious Neurological Disease," (1977) 4 Clinics Perinatol, 200-204.

175. Supra n.167 at 141.

176. R.B. Zachary, "Ethical and Social Aspects of Spina Bifida," (1968) 2 Lancet, 274.

177. Id., at 274.

178. R.B. Zachary, "The Neonatal Surgeon," (1976) 2 Br Med J, 869.

179. Id., at 869.

180. Id., at 869.

181. Id., at 869.

182. R.B. Zachary, "Life with Spina Bifida," (1977) 2 Br Med J, 1461.

183. Supra n.178 at 869.

184. Richard H. Gross et al., "Early Management and Decision Making for the Treatment of Myelomeningocele," (1983) 72 Pediatr, 450.

185. Id., at 452.

186. Id., at 457. For a critique of Gross et al's approach see John M. Freeman, "Early Management and Decision Making for the Treatment of Myelomeningocele: A Critique," (1984) 73 Pediatr, 564, in which Freeman criticizes the lack of data and reasoning as to why some infants with similar levels of lesions were recommended for treatment while others were not.

187. Id., at 456. Nonetheless all of the infants given supportive care died. However, the authors admit that they are uncertain of the cause of death of most of these infants since few autopsies were performed, although they suggest that some of the deaths may have been caused by "respiratory tract difficulties secondary to brain dysfunction combined with an acute infectious process".

188. Id., at 452.

CHAPTER TWO - THE LAW

I. Introduction

A number of substantive and procedural legal issues arise in the context of making treatment decisions for seriously ill and defective infants. The first section of this Chapter will address the issue of consent to medical treatment. The primary question in this area is, who has the right to consent to medical treatment for an infant? Subsidiary issues under this heading include, *inter alia*: (1) What information must the decisionmaker be provided with in order to give a valid consent to treatment? (2) In what situations may consent be dispensed with? and (3) What legal mechanisms exist for overriding and/or providing a legally valid consent where the decisionmaker refuses or is unable to consent to treatment for an infant?

Under the heading of "Administration of Treatment," physicians' duties to their patients will be examined as well as the sanctions which may be imposed for breaching these duties.

The next section will discuss the issue of withholding treatment (passive euthanasia). American, British and Canadian caselaw will be reviewed and compared in order to determine: (1) What criteria may lawfully be considered by decisionmakers in deciding to withdraw treatment from seriously ill and defective infants? (2) When will the courts override such decisions? and (3) Whether judicial involvement is necessary in all or only in certain cases.

In the final section of this Chapter, the legal distinction between "active" and "passive" euthanasia will be analyzed and discussed.

II. Consent to Treatment

A. Requirements for Valid Consent - Civil Law

The common law has long recognized the right of an individual to be free from unwanted bodily contact. [1] This right is operative within the context of medical treatment and has been expressed as "the right of a patient to decide what, if anything, should be done with his own body." [2] Thus, a doctor may neither touch nor treat a patient without the patient's consent, no matter how beneficial the treatment or unreasonable the patient's refusal. [3]

A physician who treats a patient without his consent (apart from emergency situations) commits a trespass and may be sued by the patient for the torts of assault or battery. [4] An action in battery will also lie where treatment is given which differs from or exceeds that which is consented to, or where the patient's consent was obtained through fraud or misrepresentation and is thereby vitiated. [5]

In order for a patient to give a valid consent to medical treatment he must be given adequate information upon which to base his decision. The law therefore imposes a "duty of disclosure" upon physicians, to impart the information that a reasonable person in the patient's position would want to know before making a decision on whether to undergo treatment.

The scope of this duty of disclosure has been defined by the Supreme Court of Canada in Hopp v. Lepp [6] and was amplified by the Court in Reibl v. Hughes, where Chief Justice Laskin, speaking on behalf of the Court, stated: [7]

> In summary, the decided cases appear to indicate that, in obtaining the consent of a patient for the performance upon him of a surgical operation, a surgeon, generally should answer any specific questions posed by the patient, as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation.
>
> ... even if a certain risk is a mere possibility which ordinarily need not be disclosed, yet if its occurrence carries serious consequences, as for example paralysis or even death, it should be regarded as a material risk requiring disclosure.

In addition to disclosing the risks of the recommended treatment, a physician must also, where the circumstances require it, explain to the patient (or guardian) the consequences of leaving the condition untreated, and alternative means of treatment and their risks. Laskin, C.J.C., expressed approval of this principle as enunciated in Canterbury v. Spence, the leading American authority on informed consent, stating:[8]

> A useful summary of issues on which medical evidence in non-disclosure cases remains significant is found in a Comment, New Trends in Informed Consent (1975), 54 Neb.L.Rev. 66, at p.90, where after noting that medical evidence should not control determination of the breach of the standard of care, it continued, as follows (referring to Canterbury v. Spence (1972), 464 F 2d 772):

> "... Even *Canterbury* specifically notes that expert testimony will still be required, in all but the clearest instances, to establish (1) risks inherent in a given procedure or treatment, (2) *the consequences of leaving the ailment untreated, (3) alternative means of treatment and their risks*, and (4) the causes of the injury suffered by the plaintiff patient. ..."
> (underlining added).

The duty to disclose existing alternative treatments has since been explicitly recognized in several lower court decisions.[9] In *Haughian v. Paine*,[10] the Saskatchewan Court of Appeal held that a neurosurgeon had breached the standard of care expected of him with respect to proper disclosure of information by failing to advise the patient of a non-surgical, alternative treatment and in failing to advise the patient of the risk of paralysis associated with the surgery. Sherstobitoff, J.A., speaking for the court, observed:[11]

> A significant factor is that the trial judge considered failure to warn of the risk of paralysis, and failure to advise of alternatives to surgery, independently of, and in isolation from, each other. These two elements of informed consent have, on the facts of this case, a strong bearing on each other. One cannot make an informed decision to undertake a risk without knowing the alternatives to undergoing the risk.

A similar view was taken by the Alberta Court of Appeal in Zimmer v. Ringrose.[12] The plaintiff in Zimmer alleged that the defendant had failed to obtain her informed consent to a sterilization procedure which had proven to be ineffective. The trial judge found that there was no comparison given by the doctor between his method and other methods of effecting sterilization. On appeal, Prowse, J.A., dealing with the extent of disclosure required, observed that the duty of disclosure was not limited to disclosing to the patient all of the risks involved in the recommended procedure or treatment, rather [13]

> ... the physician or surgeon should also discuss the benefits to be gained from the recommended treatment or operation, the advantages or disadvantages associated with alternative procedures and the consequences of foregoing treatment. Such a discussion is essential since a patient cannot measure risks in the abstract. To discharge his duty of care, the doctor must give the patient some yardstick against which he can assess the options available to him.

The Court also found the physician's disclosure inadequate in Zimmer since he did not inform the patient that the sterilization procedure performed was unique to him and not in general use by other physicians. Insofar as this aspect of disclosure was concerned, Prowse, J.A. commented: [14]

> Furthermore, the appellant failed to apprise Mrs. Zimmer of the fact that the silver nitrate technique had not been approved by the medical profession. A reasonable practitioner would have made such a disclosure for he would have realized that this information would likely influence his patient's decision whether to undergo the procedure. In view of his failure to satisfy this duty of care, I must conclude that the appellant's conduct was negligent.

Similarly, in Coughlin v. Kuntz,[15] the British Columbia Supreme Court held an orthopaedic surgeon liable for failing to obtain the patient's informed consent to a cervical discectomy. Cohen, J. found that the defendant had failed to advise the plaintiff that the procedure he performed was experimental in nature and had been questioned by other physicians.

This aspect of disclosure is extremely important in the context of neonatal care since many of the procedures and therapies are new and unproven and may be considered experimental.

It is unclear, however, whether physicians must advise the patient (or guardian) of every alternative. Two recent Ontario decisions have suggested that this is not required in every case and is a matter for physicians' judgment. In Bucknam v. Kostuik,[16] an orthopaedic surgeon performed a serious operation (fusion to the sacrum and Harrington instrumentation) on a patient without advising her that a less serious operation existed. At trial, the surgeon testified that he did not advise the patient of the alternative (a single fusion) since he had concluded that the more serious procedure was the only appropriate procedure for the patient. Krever, J. commented: [17]

> It seems to me that it may well be imposing an unreasonable standard on an orthopaedic surgeon, who reasonably believes that to treat the patient's scolious is a necessity and that a simple fusion at the area of the proven ruptured disc is not the answer to the plaintiff's problem, to require him to inform the patient of that option, an option that, by definition, in his or her mind is entirely unreasonable.

A similar conclusion was reached by Griffiths, J. in Bonnell and Bonnell v. Moddel, Dickie and Scarborough General Hospital. [18] The Plaintiffs in Bonnell alleged that the physician had failed to obtain the informed consent of the female plaintiff to an angiogram procedure because he did not discuss the advantages and disadvantages of alternative, less risky pocedures such as a cat scan or a further lumbar puncture with her. The doctor in this case, as in Bucknam, did not believe there were any other reasonable alternative procedures to the angiogram and therefore did not discuss any alternatives with the patient. Mr. Justice Griffiths reasoned: 19

> It seems to me that the principle stated in the Ferguson and Zimmer cases that the physician is under a duty to disclose the alternatives to the recommended procedure and risks of those alternatives, should be limited to the case where in the opinion of the physician the alternative procedures offer some advantage and are reasonably likely to achieve a beneficial result. If there is a duty in law cast upon the physician to discuss even those alternative procedures that the physician will frankly explain to the patient as having no diagnostic value, then applying the objective test of Reibl v. Hughes, the reasonable patient is likely to reject the alternative.

An alternative view has been expressed by Sherstobitoff, J. in Haughin (supra) who stated when discussing a physician's failure to advise the plaintiff of the available options, that: 20

> While it may have been open to the respondent not to recommend these options by way of treatment, the patient was entitled to be advised that these alternatives were open to him.

It is submitted that this approach is preferable. The prudent doctor should presume that full disclosure is required in the majority of cases. Chief

Justice Laskin cautioned physicians against taking it upon themselves to limit the information given to their patients, commenting: [21]

> A surgeon is better advised to give the warning, which may be coupled with a warning of the likely consequence if the treatment is rejected. ... It should not be for the physician to decide that the patient will be unable to make the choice and, in consequence, omit to warn him of risks.

The Court also added that the scope of disclosure required would depend upon the circumstances arising in a particular case. Thus, the doctor's obligation to disclose information will be affected by the patient's intellectual capacity and emotional ability to accept the information. These factors may render a patient "unable to cope with facts relevant to recommended surgery or treatment and the doctor, may in such a case, be justified in withholding or generalizing information as to which he would otherwise be required to be more specific". [22] On the other hand, a greater degree of disclosure will be required where a patient is inquisitive [23] or where the treatment or procedure is elective rather than mandatory. [24] Finally, a patient may waive his right to disclosure altogether, preferring instead to undergo treatment whatever the risks. [25]

The physician may also have a responsibility in addition to making the disclosure to ensure that the patient comprehends the information that is given. In Reibl v. Hughes, the Supreme Court discussed the physician's responsibility in this regard by stating,[26]

> ... it must have been obvious to the defendant that the plaintiff had some difficulty with the English language and that he should, therefore, have made certain that he was understood.

One legal commentator has suggested the test should be "that the doctor must take reasonable steps in relation to the particular patient to ensure that he understood and that objectively, or apparently, he did."[27]

Failure to properly inform a patient of the nature and material risks of a treatment or procedure may subject the doctor to an action in negligence for breach of his duty of care to adequately inform the patient. For liability to be found, however, there must be a causal connection between the doctor's inadequate disclosure and the patient's resulting harm. Thus, liability will attach to the doctor's failure to make proper disclosure if no reasonable person in the patient's position would have consented to the treatment had a proper disclosure been made.[28] Where liability is found, the doctor is liable for all of the patient's damages, including damages caused by non-negligent treatment. [29]

In order to constitute an effective defence to actions in battery or negligence, a patient's consent must meet certain other requirements. It must be voluntary, it must be specifically referable to the treatment that is given and finally, it must be given by a patient who has capacity. [30] A consent which fails to meet any one of these requirements will be found to be invalid.

A voluntary consent has been defined as, "the act of a person who is so situated as to be able to exercise free powers of choice without inducement or any element of force, fraud, deceit, duress or other form of constraint or coercion." [31] Whether a consent has been voluntarily given will be assessed in light of the circumstances which surround a particular case and the burden of proof of the voluntariness of the consent is on the doctor. [32] Margaret Somerville, the author of a Law Reform Commission Study Paper entitled, Consent to Health Care, has observed that caution must be exercised in determining the voluntariness of consent. She writes: [33]

> The most pertinent of these cautions is that these coercive factors may be at their most subtle and difficult to detect, and freedom of choice most threatened, in a situation which the more powerful party believes he is acting for the benefit of the other.

The patient's consent must also be specifically referable to the treatment that is given. [34] Treatment which is more extensive or performed in a manner which has not been consented to may result in a successful suit against the doctor, even if the treatment was beneficial to the patient. [35] This issue may arise with respect to the consent forms which are used by hospitals in order to provide a written record of the patient's consent to treatment. A common feature of such forms is to employ terminology which authorizes the specific procedure or treatment, but which also allows the doctor to "carry out additional or alternative operative measures as in his opinion may be found advisable." [36] Several American courts have held that such provisions are so vague as to be unenforceable. [37] In Canada, the Ontario High Court of Justice recently considered the effect of such a provision in Pridham et al v. Nash Estate. [38] The patient in that case had signed a consent form in which she consented to an abdominal examination (a laparascopy) and to "additional procedures as may be necessary or medically advisable during the course of such procedures." The Court held that the surgeon would be entitled to rely on these general words to perform a minor surgical procedure to cure a minor problem discovered during the examination however, he would not be entitled to rely on the patient's original consent or the general consent of the above clause, to carry out major surgery. He would have been required to consult with the patient and obtain a further consent to perform a major operation.

The Newfoundland Trial Division considered the effect of a similar clause in a consent form signed by the patient in Brushett v. Cowan.[39] In Brushett, the patient brought an action in battery against a surgeon who had performed a bone biopsy during the course of performing a muscle biopsy to which the patient had consented. The surgeon sought to rely on a clause in the consent form which provided that the patient consented to "such further and alternative measures as may be necessary during the course of the operation or special procedure ... ." The court held that the clause did not constitute a waiver of the right to be informed about any other procedures that might be performed by the surgeon. Cameron, J. noted:[40]

> The best that can be said of paragraph 2 [the clause in question] is that it is a consent to perform the kinds of measures which may be covered by the privilege to deal with emergency situations.

Since the performance of the bone biopsy was not due to an emergency, the surgeon was liable to the plaintiff for battery.

A final requirement for consent to be valid is that the patient must have the legal capacity to give it. Generally, two categories of patients lack the capacity to give an effective consent: minors and adults who are incompetent by virtue of suffering from a mental disability. However, it must be emphasized that not all adults suffering from mental disabilities lack the capacity to consent, nor are all minors incapable of giving a valid consent.[41] At common law, a minor who has the capacity to fully appreciate the nature and consequences of a medical procedure or treatment performed for his benefit can give a valid consent.[42] For example, in J.S.C. and C.H.C. v. Wren,[43] the parents of a pregnant 16 year old girl sought an injunction to prevent an abortion from being performed on their daughter on the basis that she had not given her "informed consent" to the procedure. The Alberta Court of Appeal held that the daughter's consent was "informed", since she had sufficient understanding and intelligence to make up her own mind.

This situation is complicated by the fact that within Canada, certain provinces have passed legislation which arbitrarily designates certain ages at which consent can be validly given.[44] In Alberta, the Institute of Law Research and Reform issued a report in 1975, which recommended "[t]hat the general age for consent to health care be fixed at sixteen years".[45] However no legislation has yet been passed implementing this recommendation and therefore the common law is still applicable.

Infants, of course, are included among the category of minors who are unable to consent to medical treatment. As is the case with other incompetent patients, consent for medical treatment must be given on their behalf by a surrogate. Who has the right and obligation to give consent on an infant's behalf will be discussed in a later section, for now it is necessary to consider the role of consent in criminal law.

B. Consent to Medical Treatment and the Criminal Law

Does the criminal law permit medical or surgical treatment to be given to infants in the absence of parental consent? At present in Canada the criminal law is unclear because the relevant provisions of the Criminal Code were developed without current medical realities in mind and to date there have been few prosecutions of medical personnel.

Section 244 of the Criminal Code provides that all intentional applications of force to the body of another, directly or indirectly, in the absence of consent constitutes a criminal assault.[46] If the consequences are bodily harm (something more than transient and trifling) it is an assault causing bodily harm; if death is the consequence, it is manslaughter.

Given this definition, one view is that medical treatment given without consent falls within the scope of this provision and is prima facie an assault.[47] There is an "intention" to do something to the body of another person, and the act of applying force directly or indirectly has been interpreted as meaning to either "bring something into contact with the body, or to administer something."[48] Thus, an assault could include the prescribing of medication, a urine analysis or taking an x-ray.[49]

Treatment which is given pursuant to a legally-effective consent does not constitute an assault. A legally-effective consent may be authorized by law, under federal or provincial legislation or by judicial order authorizing treatment.[50]

Apart from these relatively rare cases, consent must be obtained from the patient (if competent) or his guardian (if he is incompetent). The consent must be a 'real' consent to be legally effective. Consent will be vitiated if it is obtained through coercion[51] or by fraud.[52] The patient or guardian must be aware of the "nature of the act" which is consented to, since treatment must not exceed the scope for which consent is given. However, the criminal law does not require further disclosure of the material and probable risks of treatment as is required by civil law.[53]

An alternative view is that medical treatment is not an assault given the meaning of that word in the Criminal Code. This appears to be the approach adopted by the Alberta Court of Appeal in R. v. Carriere.[54] The Court reviewed the various meanings attached to the word assault, explaining that one approach is to view assaults as applications of force likely to be disruptive of public order (public v. private assaults). A second approach would be to view assaults as applications of force intended to, or likely to cause harm where "there is no good reason." In this regard the Court included certain activities, stating[55]

> Nothing which we have said is intended to cast doubt on the accepted legality of properly conducted games and sports, lawful chastisement or correction, reasonable surgical interference, dangerous exhibitions etc. These apparent exceptions can be justified as involving the exercise of a legal right, in the case of chastisement or correction, or as needed in the public interest, in other cases. (underline added).

If the first view discussed above is correct the provision of medical treatment to an infant in the absence of a valid consent under circumstances which would ordinarily constitute an assault does not automatically result in a finding of criminal liability, since the Criminal Code specifically recognizes valid defences in cases involving the provision of medical treatment under certain conditions.

Section 45 of the Criminal Code provides:

> Everyone is protected from criminal responsibility for performing a surgical operation upon any person for the benefit of that person if
>
> (a) the operation is performed with reasonable care and skill, and
>
> (b) it is reasonable to perform the operation, having regard to the state of health of the person at the time the operation is performed and to all the circumstances of the case.

Section 45 applies not only to physicians but to anyone who renders treatment. However, it applies to surgical treatment only. The essential elements of the defence are: a requirement of benefit, the use of reasonable care and skill in performing it, and finally, that it was reasonable to perform the surgery under the circumstances.

The Criminal Code does not define "benefit", but it is submitted that the 'purpose' of the treatment must be to benefit the patient, though not necessarily the result. Thus, non-therapeutic surgical interventions on infants for research purposes would be excluded. The Law Reform Commission has suggested that the "usual meaning of benefit" which implies that the risk assumed is not disproportionate to the benefit anticipated would be an appropriate standard.[56]

Section 45 will provide a legal justification to surgical treatment, if on the whole the act was 'reasonable'. Nevertheless, certain questions regarding its applicability remain unanswered. Section 45 apparently applies when there is an absence of consent by the parent or surrogate decisionmaker, and in an emergency situation. It is not clear whether it would apply to justify surgery being performed in a non-emergency situation although the surgery is beneficial. In such cases, it would appear to be "reasonable under all the circumstances" to obtain a valid consent before instituting treatment. However, where there is an express refusal by the parent or guardian of an infant, Section 45 may well provide legal justification for surgical treatment where the refusal is unreasonable.[57] Under these circumstances, a physician could also rely on Sections 215, 216 and 217 of the Criminal Code which state:

> 215\. Everyone is under a legal duty
>
> (c) to provide necessaries of life to a person under his charge if that person
>
> (i) is unable by reason of detention, age, illness, insanity or other cause, to withdraw himself from that charge, and
>
> (ii) is unable to provide himself with necessaries of life.
>
> 216\. Everyone who undertakes to administer surgical or medical treatment to another person or to do any other lawful acts that may endanger the life of another person is, except in cases of necessity, under a legal duty to have and to use reasonable knowledge, skill and care in so doing.
>
> 217\. Everyone who undertakes to do an act is under a legal duty to do it if an omission to do the act is or may be dangerous to life.

These three sections are not defences, rather they impose duties upon those who undertake to do acts (i.e., provide medical treatment). Thus, in addition to pleading legal justification under Section 45, it would be open to the physician to argue that failing to perform surgery on the infant would have been a breach of the duties imposed by Sections 215, 216 and 217 of the Code.

Section 45 is a limited defence since it only applies to surgical procedures. Where non-surgical medical treatment is provided in the absence of a valid consent, legal justification may be found under the common law defence of necessity. [58] This defence has been considered by the Supreme Court of Canada in two recent cases, in Morgentaler v. The Queen [59] and in Perka v. The Queen. [60]

In the Morgentaler decision, Dickson, J. (as he then was) expressed reservations regarding the existence of the necessity defence in Canadian law, and concluded that, if it did exist as a defence, it was extremely narrow in scope. He wrote: [61]

> On the authorities it is manifestly difficult to be categorical and state there is a law of necessity, paramount over other laws, relieving obedience from the letter of the law. If it does exist, it can go no further than to justify non-compliance in urgent situations of clear and imminent peril when compliance with the law is demonstrably impossible.

The Chief Justice again considered the defence of necessity in Perka. He reiterated the view he had expressed earlier in Morgentaler regarding the limited scope of the defence and set forth a number of conclusions regarding the basic elements and limitations of the defence as follows: [62]

> (1) Necessity should be recognized as an excuse operating by virtue of S.7(3) of the Criminal Code.
>
> (2) The essential criterion for the defence is the moral involuntariness of the wrongful action measured on the basis of society's expectation of appropriate and normal resistance to pressure.
>
> (3) The act in question may only be described as involuntary where it was inevitable, unavoidable, and where no reasonable opportunity for an alternative course of action that did not involve a breach of the law was available to the accused.
>
> (4) The defence only applies in circumstances of imminent risk where the action was taken to avoid a direct and immediate peril.
>
> (5) The harm inflicted by the violation of the law must be less than the harm the accused sought to avoid.
>
> (6) The defence may not be raised where actions and circumstances indicate that the wrongful deed was not truly involuntary. This may arise in cases where it was

contemplated or ought to have been contemplated by the accused that his actions would likely give rise to an emergency requiring the breach of the law.

(7) Mere negligence or involvement in criminal or immoral activity when the emergency arose, will not disentitle the accused from relying on the defence.

(8) Where sufficient evidence is placed before the court to raise the issue of necessity, the onus is on the Crown to prove beyond a reasonable doubt that the accused's act was voluntary.

Thus, although the necessity defence is available in Canada, the Supreme Court has made it clear that the defence has a limited application. The medical practitioner (or anyone else) who provides medical treatment to an infant in the absence of a valid consent would only be able to utilize the defence if the following conditions were met:

(1) The infant's life or health was in imminent peril or danger. (4)

(2) The involuntary criterion required will be met if the treatment given is one that would automatically be expected under the circumstances and must be performed so quickly that there is no time to obtain consent. An example would be cardiopulmonary resuscitation which is performed on a patient who is brought into a hospital suffering from a massive heart attack. (2) (3)

(3) The treatment given must be less harmful than the consequences of non-treatment. (5)

The defence of necessity would not be available to the treatment-provider under the following circumstances:

(1) Where the infant's condition could have been stabilized until a valid consent could be obtained. (3)

(2) In cases in which the physician could reasonably anticipate that emergency treatment might be required. An example would be a case where an infant is suffering from a terminal illness and it is reasonable to expect that at some point unless a No Code order is authorized, emergency resuscitative measures will be instituted. (6)

(3) In cases where another legal alternative exists, the defence of necessity will not lie. The most obvious example which comes to mind is the provision of a blood transfusion to an infant against the parents' wishes. Legal mechanisms (discussed infra) are available which will provide a legally effective substituted consent to the authorization of treatment and thereby offer a legal alternative to treating over a refusal to consent. (3).

Thus, there are three possibilities with respect to the provision of active medical treatment in the absence or refusal of parental consent:

1. It is not an assault (R. v. Carriere);
2. If it is not an assault then s.45 or the necessity defence applies;
3. Where the medical treatment (apart from surgical treatment to which section 45 applies) the possibility of other legal alternatives precludes the usage of the necessity defence, i.e., the necessity defence will only be available in exigent circumstances where there is no time or opportunity to pursue other legal alternatives (Perka).

It is submitted that the preferred alternative would be the insertion of a provision in the Criminal Code that properly conducted medical or surgical treatment does not constitute an assault as suggested in R. v. Carriere.

C. Consent to the Medical Treatment of Infants

1. Parental Consent Required

Since infants and young children are incapable of giving their consent to medical treatment, consent must be given on their behalf by others. The law has generally accorded parents the right to give a legally-effective consent to medical treatment for their children.[63]

Historically at common law the father had guardianship of his children and upon his death the mother became her children's guardian. Guardianship in socage included guardianship by nature which extended to the custody of the child, while guardianship by nurture extended to control of the infant's property as well. [64] Guardianship in socage is no longer in use in Canada and has been expressly abolished in Alberta by Section 53 of the Domestic Relations Act. [65]

Section 47 of the Domestic Relations Act provides: [66]

> Unless otherwise ordered by the Court the father and mother are joint guardians of the minor, and the mother is the sole guardian of the illegitimate minor.

The Act further provides that a guardian "may act for or on behalf of the minor" [67] which includes the right to make decisions with respect to medical treatment for the child. [68]

In addition to requirements for parental consent at common law, several provinces have enacted legislation requiring that either oral or written consent must be obtained from a parent or guardian prior to surgical or medical treatment being given to a minor patient. [69]

2. When Parental Consent is not Required

As previously discussed, the provision of medical treatment to an infant without having first obtained the parent's consent may expose the physician to criminal as well as civil liability. However, just as the criminal law recognizes a defence of necessity, civil law also recognizes that physicians may provide medical treatment under necessitous circumstances. [70] In Marshall v. Curry, [71] the Nova Scotia Supreme Court held that where a great emergency which could not be anticipated arises "a doctor is justified in acting" in order to save the life or preserve the health of the patient." [72]

To rely on the defence of necessity however, the situation must be a true emergency and not merely "convenient" that treatment be given. In Murray v. McMurchy, [73] a doctor found a number of fibroid tumors on the wall of the patient's uterus while performing a Caesarian operation. He decided to tie the patient's tubes in order to prevent a further pregnancy which could cause the growths to increase in size and constitute a potential hazard. The patient brought an action against the doctor for trespass. McFarlane, J. held that this case was distinguishable from those cases in which "it would be under the circumstances, reasonable to postpone the operation until a later date" since it was merely "convenient" to perform the operation as the patient was under an anaesthetic and there was "no evidence that these tumors were presently at the time of the operation dangerous to her life or health." [74]

Where there is a "refusal of consent" as opposed to an "absence of consent" the necessity defence is unavailable. In Schweizer v. Central Hospital, [75] Thompson, J. described nonconsensual surgical interference as an assault, adding, "[t]he only exception lies in the case of emergency where it is not practicable to obtain the patient's consent or the consent of someone on his behalf, and where the surgeon deems it necessary to immediately take action for the preservation of the life or health of the patient" [76] and in a well-known Alberta case, Mulloy v. Hop Sang, [77] a doctor was found liable for trespass for amputating a patient's hand over the patient's express refusal even though the Court found that the operation was necessary under the circumstances in order to prevent blood poisoning.

The extent to which the courts will uphold a patient's right of refusal is illustrated by the recent case Mallette v. Schulman et al. [78] In that case, a physician who administered a blood transfusion to an unconscious Jehovah's Witness, although he was aware of a card carried by the patient, flatly forbidding any form of blood transfusion under any circumstances was found liable to the patient for battery. The court held that the doctrine of informed consent had no bearing upon the right of refusal since a patient's right to refuse treatment was an absolute right.

However, a number of provinces have passed legislation which specifically exempts physicians from liability from providing surgical and/or medical treatment in emergency situations and dispenses with the requirement for parental or guardians' consent in these cases. For example, in Saskatchewan, a parent's or guardian's consent may be dispensed with in the case of a surgical operation where an emergency situation exists. [79] The surgeon must sign a statement that an emergency exists, and that delay pending the obtaining of consent would be inadvisable. However, Section 6 of Saskatchewan's Draft Act [80] is broader in scope in that, "no consent" is required for "health care" which is provided to a minor in an emergency. The Act also provides that anyone may apply to a judge for an order prohibiting health care which "is not in the interests of the continuing health and well-being of the recipient and where the health care recipient has not attained the age of sixteen years."[81] Where a "judge is satisfied that the health care is not in the interests of the health care recipient's continuing health and well-being, he shall prohibit the health care."[82] This proposed legislative provision thus provides specific legislative recognition of the fact that there are circumstances in which continued treatment, and by implication, continued life may not be in a child's best interests, and this provision would be relevant in cases involving seriously ill and defective infants.

Alberta's Draft Act[83] provides that where a parent or guardian's consent is refused or is unobtainable, any person may apply to the court for an order dispensing with consent. If the court is satisfied that the withholding of medical treatment would "endanger the life or seriously impair the health of the minor" it may issue an order dispensing with consent.[84] New Brunswick's Medical Consent of Minors Act contains provisions which are identical.[85]

Manitoba provides an exemption from the requirement for written consent in the case of surgical operations providing that the surgeon is of the opinion that there is an emergency and the delay caused by the obtaining of consent might endanger the life of the patient. [86] The surgeon is required to document the above by a written report in which he states his opinion and reasons for failing to obtain written consent. Once he has done so, the operation may be performed. [87] The statute provides for an exception to complete documentation in an emergency but requires the physician to complete a written post-surgical report giving the reasons for the lack of documentation and his pre-operative diagnosis. [88]

In Ontario, the government has passed regulations under The Public Hospitals Act [89] which dispenses with parents' or guardian's written consent to surgical operations on children under 16 "where the surgeon believes that delay caused by obtaining the consent would endanger the life, or a limb or vital organ of the patient and the surgeon must sign a written statement to that effect. [90] It should be noted that the validity of these regulations was doubted by the Supreme Court in Re Eve. [91]

In Quebec, a mandatory obligation is imposed upon hospitals and physicians to provide "care or treatment to every person in danger of death, if the person is a minor, the consent of the person having parental authority shall not be required." [92] Thus, under Quebec's legislation a physician must override a parent's refusal to consent to life-saving treatment in an emergency situation.

Other provinces such as New Brunswick (and Alberta under its Draft Act) also permit treatment to be given where a parent has refused consent but require the physician to obtain a court order dispensing with consent.

Saskatchewan, Manitoba and Ontario's legislation, on the other hand, deal only with the dispensing of consent in cases where there is a delay caused by the obtaining of a parent or guardian's consent. Thus, in these provinces, if there is no delay caused by obtaining the parent's consent or the parents refuse their consent, the legislation is inapplicable.

While these statutes provide the doctor with some degree of protection from liability for the provision of non-consensual medical treatment to infants they offer only partial protection. Many of the statutes deal only with the dispensing of consent for surgical treatment while others apply only to public (Ontario) or private (Manitoba) hospitals. [93] In circumstances which lie beyond the scope of the various statutes and in those provinces and territories which do not have legislation addressing the dispensing of consent, doctors must rely on the common law emergency doctrine to provide justification for non-consensual medical treatment. In raising the emergency defence physicians are assisted by the Canadian Medical Association's Code of Ethics which requires a doctor to provide treatment he "believes to be in the patient's best interests" if the patient is unable to consent and an agent is unavailable." [94] Joseph Magnet maintains that "[t]his amounts to a virtual legal duty for the physician because the torts system has scrupulous regard for documents such as the Code of Ethics." [95]

The Code of Ethics, the common law emergency doctrine and the majority of the principal statutes dealing with consent are silent regarding physicians' obligations in the face of a parent or guardian's refusal to consent to medical treatment for an infant. The options the physician has when this occurs will be discussed in the following section of the paper.

3. Parental Refusal of Consent

While it is clear that parents have the right to make medical decisions for their infants and young children [96] it is less clear at what point the State may intervene and override these decisions. Professor Bernard M. Dickens, of the University of Toronto, addresses this issue in an article entitled, "The Modern Function and Limit of Parental Rights" [97] in which he describes the nature and extent of parental obligations to their children. In Dickens' view: [98]

> The modern function of parental rights ... is to permit parents to discharge their duties to their children. These duties are not positively to do good, but to avoid harm. It is obvious that to the extent that ill health and, for instance, illiteracy are considered harm, parents are bound by positive duties to provide health care and education ... The duty to avoid harm is more elastic, however, since it affords licence to control a child not for its benefit, but in non-beneficial or non-therapeutic ways falling short of causing or risking harm. The issue to be critically addressed is the point at which an exercise of parental choice over a child's management and future is so potentially harmful to the welfare or interests of the child as to require state intervention and possibly a countermanding of parental choice.

Dickens submits that state intervention is clearly justified in cases where a parent's refusal to consent to treatment would result in an avoidable or premature termination of an infant's life, [99] and that parental rights may also be curtailed when parents attempt to make decisions for a child which would prevent the child from exercising future options in life, for example, parents deciding to have their child sterilized.[100]

He concludes that the state may also intervene when parents choose treatment which is harmful, medically ineffective[101] or unavailable. An example of the latter occurred in Re Wintersgill[102]. The parents were Jehovah's Witnesses who refused to consent to a blood transfusion for their premature infant but did consent to alternative conservative therapy. A physician was found who was willing to provide this treatment, but only if the child was removed from a respirator. All of the parties (including the parents) agreed that the child could not be removed from the respirator and that as long as it needed the respirator it would have to remain in the neonatal intensive care unit where it was currently being treated. However, the doctors in the unit believed that blood transfusions constituted the only effective treatment for the child and refused to attempt the conservative therapy. In ordering that the transfusions be given to the infant, Carter, J. reasoned:[103]

> I do not think it is for me to pick and choose between one method of caring for a premature baby and another. It is true that the parents are not obliged

> to provide the best and most modern methods. They must provide the care which a duly qualified medical practitioner deems essential to the life and health of the child. I have modified that word by using the word "available". They have satisfied me that they will have done so when Dr. Mills is ready to take the baby.

When parents refuse to consent to medical treatment for their infants, physicians can invoke the aid of child welfare authorities or they may apply to the courts for an order authorizing treatment.

(a) Child Welfare Authorities

In Canada, provincial child welfare authorities are charged with the responsibility of protecting children who are "in need of protection" as defined by the various provincial Child Welfare Acts.

Under Alberta's Child Welfare Act a child is in need of protective services if ... the survival, security or development of the child is endangered because[104]

> the guardian of the child is unable or unwilling to provide the child with necessities of life, including failing to obtain for the child or to permit the child to receive essential medical, surgical or other remedial treatment that has been recommended by a physician.

All of the other provincial statutes have similar provisions.[105] For example, Ontario's Child and Family Services Act provides that, if "the child suffers from a mental, emotional or developmental condition that, if not remedied, could seriously impair the child's development and the parents are unable, unavailable or refuse to provide treatment to prevent the child from harm, then that child is in need of protection."[106]

When a child is deemed to be in need of protective services the statutes permit the child to be apprehended.[107] In Alberta, once a child has been apprehended, the director may:[108]

> authorize the provision of any essential medical, surgical, dental or other remedial treatment that is recommended by two or more physicians or dentists, as the case may be, without the consent of the guardian of the child.

Quebec permits emergency medical treatment (urgent measures) to be given for only twenty-four hours before a court order authorizing treatment must be obtained and the child's parents must be consulted, although their refusal to consent may be overruled. This court order is only effective for five working days.[109] After this time, the director may enter into a voluntary agreement with the parents that the child receive certain health services or he may apply to the court for a judicial determination.[110]

Under Ontario's new Child and Family Services Act, a child protection worker may consent to a child's medical examination after apprehension, but there is no provision for an apprehending official to consent to medical treatment in the absence of a court order.[111]

Prince Edward Island's statute provides that where the child is suffering from a "serious" medical condition requiring treatment, the director shall notify the parent or guardian and attempt to obtain their written consent to authorize treatment. If their consent cannot be obtained, the director may then authorize the treatment.[112]

All of the other provinces permit child welfare officials to consent to emergency medical treatment without obtaining prior judicial approval.[113]

However, in Alberta where a child has been apprehended because of the guardian's refusal "to permit essential medical, surgical or remedial treatment that is recommended by a physician", the director is required to apply to the court for an order authorizing treatment. [114] The child's guardian must be given notice of the hearing at least one day before the hearing, although the court may dispense with service of notice or "authorize the giving of a shorter period of notice." [115] A hearing must be held not more than 10 days after the date the child was apprehended. [116] If the court is satisfied that treatment is in the child's "best interest" the court may override the guardian's refusal to consent and authorize treatment. [117] The statute also exempts a physician from liability for providing treatment to a child over a guardian's refusal when treatment is provided "pursuant to an order under this section." [118] Thus, the legislation obviates the need for a physician to rely on the common law doctrine of emergency when seeking to provide medical care to a child when the parents or a guardian refuses to consent to treatment. [119]

When a court finds that a child is "in need of protection" the court may award guardianship of the child to the Crown or to a child welfare agency on either a temporary or permanent basis. [120] On obtaining a guardianship of the child, the Crown or relevant agency is then empowered to consent or refuse medical treatment on the child's behalf.

Most provincial child welfare statutes require decisionmakers to consider the "best interests of the child" in rendering their decisions, as defined by the statute in question.[121] Section 20(5) of Alberta's Child Welfare Act[122] states:

> If it is satisfied that the treatment is in the best interests of the child, the Court may authorize the treatment notwithstanding that the guardian of the child refuses to consent to the treatment.

Further guidance is provided under Section 2 of the Act which sets out the criteria which must be considered by the decisionmaker in rendering a decision. The following factors are applicable to decisions regarding the medical treatment of infants:

> (i) the provision of protective services is intended to remedy or alleviate the condition that caused the child to be in need of protective services;
>
> (j) if a child is being provided with care under this Act, the child should be provided with a level of care that is adequate to meet the needs of the child and consistent with community standards and available resources;
> (emphasis added).

The court (or any other decisionmaker, i.e., the director) may only intervene where a child is found to be "in need of protection". As previously discussed, a child will only be in need of protection under the Alberta statute, if the parent or guardian refuses or is unable to provide the child with "essential, medical, surgical or other remedial treatment."[123] If the treatment is merely beneficial and cannot be classified as "essential" there is no justification to interfere with a parent or guardian's decision.[124]

The medical treatment that is required under the Act, in addition to being "essential" must be able to "remedy or alleviate" the infant's condition. Therefore, where a child's condition is such that treatment is futile or harmful, that child cannot be considered in need of protection, when the parents or guardian refuse to permit such treatment.

In requiring that the treatment be "consistent with community standards" the Act provides that the decision to consent or refuse medical treatment must be based upon an objective standard which is set by the community into which the child is born. Simply put, all infants born in Calgary, Alberta suffering from "x" defect or condition are entitled to "y" treatment. Thus, it will be necessary for the courts to examine the treatments currently given by Calgary neonatologists in similar cases.

Joseph Magnet has observed that generally the "customary" practices of the medical profession will be considered by the courts as a "compelling, although not conclusive, indication that treatment is appropriate, and in the child's best interests."[125] Two recent Alberta cases support this conclusion. In each case, the courts considered an application by provincial authorities under Alberta's Child Welfare Act[126] for the temporary guardianship of a premature infant to enable the child to receive blood transfusions. The applications were granted in each case based upon testimony given by the attending neonatologists although contradictory medical evidence was presented to the court.

In Re R.K.,[127] the two attending neonatologists testified that even with the blood transfusions the mortality rate for infants with R.'s condition was 65-75% and that if no transfusions were given it would be close to 100%. The court also heard the testimony of three outside experts brought in by the parents who testified that the transfusions were not essential. One was an expert in "adult" hematology who did not treat pediatric cases, another was an obstetrician who sent premature infants delivered at his hospital to another hospital, while the third physician was an expert in pediatrics, although he was an administrator who had not actively treated any premature infants since 1977. However, the attending neonatologists' views were buttressed by the testimony of a pediatric hematologist who gave rebuttal evidence. Russell, P.C.J. commented in assessing the medical evidence:[128]

> In this case, the physicians who have been, are now and will continue to be responsible for the treatment of R. are firmly of the view that it is essential and will continue to be for some time that blood transfusions be available for the treatment of this baby. In my view, they have made earnest efforts to accommodate the wishes of these parents in modifying the standard treatment provided to babies in these circumstances. But they are adamant that there is a lower limit to the acceptable standard of care essential for this baby's health and survival. In weighing the expert testimony before me, I prefer to rely on the evidence of physicians who have and will continue to assume the full professional and legal responsibility for the total care of this child, and who have the expertise in a sub-specialty of medicine which is uniquely specialized in the complex care of babies in R.'s condition.
>
> In the view of those physicians the alternative forms of care proposed by

> the parents are untried and unproven. ... It is clear that this court could not and should not direct the hands of these physicians ...

However, the court pointed out that it could "stay the hands" of the physicians if the treatment which they recommended was not essential and cited four different situations in which that finding could be made: 129

> (1) where without treatment the child's life or health would not be endangered;
>
> (2) where the proposed treatment would not significantly improve his chances for survival or state of health;
>
> (3) where the treatment recommended presents greater risks to the life or health of the child than the condition itself; or
>
> (4) where another equally safe alternative form of treatment is readily available.

Under the circumstances, Judge Russell found that without the blood transfusions "this baby's life or quality of life is endangered." 130 and therefore they constituted an essential treatment.

In M. v. Dir. of Child Welfare, 131 the trial judge also concluded that blood transfusions constituted essential medical treatment for an extremely premature infant. Three neonatologists from the Foothills Hospital neonatal intensive care unit each testified that without blood transfusions the infant would die and that with them she had a 50/50 chance of survival. The court also heard evidence from a doctor called by the parents that there was medical opinion which supported the conservative approach (not requiring a blood transfusion) requested by the parents. In addition, the court heard testimony of Dr. Kluge, an expert in medical ethics, that the aggressive approach of the neonatal intensive care team was not mandatory from an ethical standpoint given the extreme prematurity of the infant. In assessing the evidence before him, the trial judge concluded: [132]

> However, I prefer the evidence of Doctors Wallen, Singhal and Sauve, all of whom agree that the risks of the transfused blood containing contaminants is very low, and that it is imperative that the neonatal unit be able to administer the transfused blood to S. ...

On appeal, Virtue, J. upheld the trial judge's decision, stating: [133]

> In seeking to determine whether blood transfusions were essential medical services in this case, he was applying the correct test under the Child Welfare Act. I am satisfied that he did not misapprehend or disregard

> evidence but that he weighed it carefully and fairly. That being the case, his decision, in my respectful view, should not be disturbed on this ground of appeal.

Thus, the evidence of local neonatologists is highly persuasive to the courts in determining whether medical treatment is in a child's "best interests" and is in accordance with community standards. Although the courts are prepared to hear evidence from other doctors or non-medical experts, there is not surprisingly, much greater weight given to the evidence of neonatologists who are skilled specialists in dealing with these kinds of cases and who would ultimately be responsible for providing the infant's care while the child is in the neonatal unit.[134]

Finally, the Act introduces a limit to the provision of medical treatment required pursuant to the Act. Treatment need only be given that is consistent with "available resources". There is no requirement that infants be given treatments which are prohibitively expensive, or highly experimental such as artificial hearts and lungs. However, these are policy decisions which will normally be made by provincial health ministeries or hospital administrators based upon economic considerations and other predetermined criteria rather than by the courts or individual doctors [135], although a court could rule that such a treatment was "extraordinary" and therefore not required in a particular case.

(b) The Courts' Parens Patriae Jurisdiction

The *parens patriae* jurisdiction was originally exercised by the Sovereign who had care and control over both the person and property of mental incompetents. [136] This jurisdiction was considered by Lord Eldon in *Wellesley v. Duke of Beaufort*, who stated: [137]

> ... it belongs to the King as *parens patriae*, having care of those who are not able to take care of themselves, and is founded on the obvious necessity that the law should place somewhere the case of individuals who cannot take care of themselves, particularly in cases where it is clear that some care should thrown round them.

The *parens patriae* jurisdiction was later transferred to the Court of Wards and Liveries where the jurisdiction was then exercised by the Lord Chancellor.

Wardship of children evolved as a separate institution arising out of the feudal system of tenures. The purpose of wardship was to provide care and control over the person and properties of the heir. This jurisdiction was also administered by the Court of Wards until the system of tenures was abolished. The Court of Wards itself was subsequently abolished and following its dissolution the _parens patriae_ jurisdiction became vested in the Court of Chancery, which extended the jurisdiction to infants in addition to the mentally incompetent.[138] In _Re Eve_, La Forest, J. of the Supreme Court of Canada observed:[139]

> In time wardship became substantively and procedurally assimilated to the _parens patriae_ jurisdiction, lost its connection with property and became purely protective in nature. Wardship thus is merely a device by means of which Chancery exercises its _parens patriae_ jurisdiction.

The _parens patriae_ jurisdiction later became vested in the provincial Superior Courts of Canada which continue to exercise this jurisdiction today.[140]

There is no apparent limit on the scope of the jurisdiction. Latey, J. in _Re X_, noted:[141]

> ... I can find nothing in the authorities to which I have been referred by counsel or in my own researches to suggest that there is any limitation in the theoretical scope of this jurisdiction; or, to put it another way, that the jurisdiction can only be invoked in the categories of

> cases in which it has hitherto been invoked, such as custody, care and control, protection of property, health problems, religious upbringing and protection against harmful associations. The list is not exhaustive.

This view of the broad ambit of the Court's jurisdiction was approved by the Supreme Court of Canada in Re Eve.[142] The jurisdiction also extends to cases of apprehended injury as well as to cases where the harm or injury has already occurred.[143]

There is no doubt that the Courts may exercise the *parens patriae* jurisdiction to authorize or to refuse medical treatment for a seriously ill infant. In Re S.D.,[144] the British Columbia Supreme Court utilized the jurisdiction to authorize a shunt revision operation on a severely handicapped child whose parents had refused their consent, while in Re Eve,[145] the Supreme Court of Canada exercised the jurisdiction to refuse a parent's application for a non-therapeutic sterilization of her mentally retarded daughter.

The principle which governs the exercise of the *parens patriae* jurisdiction has been repeatedly stated by the courts to be the "best interests" of the child. Nevertheless, English courts permit the interests of others to be considered and weighed in exercising the wardship jurisdiction. In Re X,[146] the court permitted the publication of a book which detailed the ward's father's depraved sexual practices although the publication would likely be harmful to the ward, on the basis that the interests of the child could not prevail over the wider interests of freedom of publication. In ordering publication, Sir John Pennycuik noted that, "[t]he court must hold a proper balance between the protection of the ward and the rights of outside parties."[147] Similarly, in Re L,[148] the court ordered blood tests to determine an infant's paternity because the tests were not only in the child's best interests but the adult parties' interests as well.

However, the Supreme Court of Canada has recently held that the interests of others are not to be considered when exercising the court's parens patriae jurisdiction.[149] In Re Eve, the Court examined the purposes of a proposed sterilization of a 24 year old mentally retarded woman and found that the proposed surgery had three purposes: (1) to protect Eve from the possible trauma of giving birth and the purported difficulties she would have in attempting to parent a child, (2) to relieve her of the hygenic tasks associated with menstruation, and (3) to relieve Eve's mother of the anxiety and worry that Eve might become pregnant. The Court considered the latter purpose first and rejected it as a basis for the exercise of the jurisdiction. La Forest, J., who wrote the unanimous opinion of the Court, explained:[150]

> Though the scope or sphere of the operation of the parens patriae jurisdiction may be unlimited, it by no means follows that the discretion to exercise it is unlimited. It must be exercised in accordance with its underlying principle. Simply put, the discretion to do what is necessary for the protection of the person for whose benefit it is exercised: ... The discretion is to be exercised for the benefit of that person, not for that of others. It is a discretion, too, that must be at all times exercised with great caution, a caution that must be redoubled as the seriousness of the matter increases. This is particularly so in cases where a court might be tempted to act because failure to do so would risk imposing an obviously heavy burden on some other individual.

In applying these principles to the facts of the present case, he noted:[151]

> One may sympathize with Mrs. E. To use Heilbron, J.'s phrase, it is easy to understand the natural feelings of a parent's heart. But the parens patriae jurisdiction cannot be used for her benefit. Its exercise is confined to doing what is necessary for the benefit and protection of persons under disability like Eve. And a court, as I previously mentioned, must exercise great caution to avoid being misled by

> this all too human mixture of emotions and motives. So we are left to consider whether the purposes underlying the operation are necessarily for Eve's benefit and protection.

The reasons advanced in support of Eve's sterilization - the trauma of giving birth, her unfitness as a parent and menstrual hygiene were considered to be "demonstrably weak" and thus failed to satisfy the Court that sterilization would be in Eve's "best interests". La Forest, J. concluded: [152]

> The grave intrusion on a person's right and the certain physical damage that ensues from non-therapeutic sterilization without consent, when compared to the highly questionable advantages that can result from it, have persuaded me that it can never safely be determined that such a procedure is for the benefit of that person. Accordingly, the procedure should never be authorized for non-therapeutic purposes under the parens patriae jurisdiction.

Thus, in Canada, a parent or guardian can consent to a 'therapeutic' sterilization but no one, including a superior court can consent to a non-therapeutic sterilization for an incompetent person.

What are the implications of Re Eve with respect to decisions regarding medical treatment for handicapped infants? It is submitted that there would be very few circumstances in which a court would sanction a refusal to consent to treatment in exercising its parens patriae jurisdiction.

First, the refusal of medical treatment in such cases would likely result in the infant dying or the possibility that the child might survive but in a worsened condition, and the results are irreversible.[153] In Eve, the Supreme Court emphasized the irreversibility of sterilization and the near impossibility of correcting an error by later judicial decision.[154] Quoting from Lord Eldon's dictum in the Wellesley's case, La Forest, J. noted that, "it has always been a principle of this court not to risk the incurring of damage to children ... which it cannot repair, but rather to prevent the damage being done."[155]

A further consideration cited by the Court in refusing to permit Eve to be sterilized was the possibility that nature or new medical discoveries might possibly relieve Eve of her incapacities. La Forest, J. commented: "Such a possibility should give the courts pause in extending their power to care for individuals to such irreversible action as we are called upon to take here." [156] These considerations would equally apply to refusing life-saving treatment from defective infants whose futures are more uncertain than Eve's.

The Court also rejected the exercise of the _parens patriae_ jurisdiction as a method of solving social problems. Although it recognized that mentally incompetent parents may have difficulty in coping with parenthood, the Court submitted: [157]

> ... this issue does not relate to the benefit of the incompetent, it is a social problem, and one moreover that is not limited to incompetents. Above all it is not an issue that comes within the limited powers of the courts, under the _parens patriae_ jurisdiction, to do what is necessary for the benefit of persons who are unable to care for themselves. Indeed, there are human rights considerations that should make a court extremely hesitant about attempting to solve a social problem like this by any means.

Thus, many commonly cited reasons for withholding life-saving medical treatment from defective infants such as the possibility of life in an institution, lack of community programs, and lack of educational and employment opportunities would be considered to be social problems lying beyond the scope of the courts _parens patriae_ jurisdiction.

The courts will consider the child's physical, emotional and mental health in making a decision, and although non-therapeutic sterilization is not permitted, the Supreme Court has not foreclosed the possibility that other non-therapeutic interventions might be permissible under certain circumstances. The Court referred to a decision in which an American court permitted a kidney transplant from a retarded child to a sibling.[158] In this regard, La Forest commented:[159]

> Whether the courts in this country should go that far, or as in Quinlan, permit the removal of life-sustaining equipment, I leave to later disposition.

Justice La Forest's remarks suggest that it would be open to Canadian courts to authorize the removal of life-sustaining treatment when an infant has no hope of recovery from a permanent vegetative state.

There are several benefits to physicians in invoking the courts' common law wardship jurisdiction, when parents refuse to consent to treatment for their infants. There are no "statutory formalities" such as time limitations involved, as is the case under child welfare statutes. The court's jurisdiction can be speedily engaged and each party (including the infant) may be represented by counsel. In addition, the court may call and consider any evidence it considers to be necessary in reaching a decision. Thus, the commmon law wardship jurisdiction offers a readily available mechanism for resolving disputes which may arise between parents and physicians over the treatment of seriously ill and defective infants.

D. Criteria Governing Treatment Decisions

What criteria may be lawfully considered in making decisions regarding the provision of medical treatment to defective infants? Can non-medical criteria be lawfully considered? Such criteria may include the parents' marital status, income level, intelligence and education, attitude towards the child, impact of the child on the parents' marriage, and the effect the child would have on its siblings.

1. Doctors

Although physicians will often take non-medical factors into account in assessing whether a child should be given medical treatment or not, it must be remembered that it is the parents (or guardians) who are legally entitled to make the decision regarding the infant's treatment unless their guardianship is interfered with.

As discussed in Chapter One, neonatologists consider non-medical factors in recommending treatment or non-treatment. These non-medical criteria are thought to be conducive to or detrimental to the child's potential for development and therefore are weighed along with purely medical criteria in decisions regarding infants' treatment. Magnet has observed however, that neonatologists often rely on information which may be inadequate or incorrect. [160] Furthermore, he points out that no scientific proof exists as to the importance or relevance of these various factors. Yet, he maintains that physicians may include such criteria in assessing an infant's treatment as long as they inform the parents of the criteria on which their recommendation is based.

It is difficult to see that the law supports this view. First, on a practical level, an assessment of medical criteria is within the scope of the physician's expertise, while evaluating non-medical criteria is not, and second, should the physician believe that the parents' ability to provide subsequent care for the child is questionable, he may contact child welfare authorities or he may invoke the parens patriae jurisdiction of the courts. The law does not distinguish between infants born to poor, 15 year old, unmarried mothers and those born to upper middle-class, married parents, nor, it is submitted, may the physician.

2. Parents

Parents, as their infant's guardians, have the right to make decisions regarding the medical treatment of their children unless their guardianship is interfered with by child welfare officials or the courts and their guardianship may only be interfered with when they are not acting in the "best interests" of their children. The law requires that medical treatment be provided where it is in a child's "best interests" and thus it is submitted that the parents may not decide to withhold medical treatment because of the negative impact the infant may have on their own lives or those of their other children.

3. Courts and Child Welfare Agencies

When the courts are involved in decisions regarding the medical treatment of infants, under their parens patriae jurisdiction the courts may consider non-medical factors in determining whether medical treatment is in a child's best interest. For example, some American courts have permitted minors to donate organs to their siblings based on a notion of psychological benefit to the donor. However, non-medical criteria based upon the interests or convenience of third parties has been rejected by the Supreme Court of Canada in Re Eve. Thus, considerations such as the effect on the parents' marriage or on other siblings may not enter the courts' determination in exercising their parens patriae jurisdiction.

Child welfare officials have no right to interfere with parental decisions regarding medical treatment for their children unless the parents or guardians fail to obtain for the child or to permit the child to receive "essential" medical treatment.[161]

Section 20(5) of Alberta's Child Welfare Act provides that a court may authorize medical treatment of a child if the court is satisfied that treatment is in the child's best interests when the guardian refuses to consent to treatment. Where physicians are unable to obtain a consent from the parents, i.e., the parents are unavailable or unable to give their consent to treatment then the decisionmaker must consider the statutory criteria set out in Section 2 of the Act. The relevant criteria are:

> 2. In exercising any authority or making any decision pursuant to this Act, a court and all persons shall consider the following:
>
> (a) the family is the basic unit of society and its well-being should be preserved;
>
> (b) the interests of the child should be recognized and protected;
>
> (c) the family has the right to the least invasion of its privacy and interference with its freedom that is compatible with its own interest, the interest of the individual family members and society;
>
> (d) the family is responsible for the care and supervision of its children and every child should have an opportunity to be a wanted and valued member of a family, and to that end
>
> (i) if protective services are necessary to assist the family in providing for the care of a child, those services should be supplied to the family insofar as it is reasonably practicable to do so in order to support the family unit and to prevent the need to remove the child from the family, and
>
> (ii) a child should be removed from the family only when other less intrusive measures

are not sufficient to protect the survival, security or development of the child;

(f) any decision concerning the removal of a child from the child's family should take into account

(iii) the risks to the child if the child remains with the family, is removed from the family or is returned to the family;

(g) if it is not inconsistent with the protection of a child who may be in need of protective services, the child's family should be referred to the community resources for services that would support and preserve the family and prevent the need for any other intervention under this Act;

(i) the provision of protective services is intended to remedy or alleviate the condition that caused the child to be in need of protective services;

(j) if a child is being provided with care under this Act, the child should be provided with a level of care that is adequate to meet the needs of the child and consistent with community standards and available resources:

(k) if a child is being provided with care under this Act, a plan for the care of a child should be developed that will address the child's need for stability and continuity of care and relationships.

These criteria must be considered by the courts and child welfare officials when making any decision under the Act. Under Section 2, the child's interests are cited as only one of the interests that should be recognized and protected. The Alberta statute does not require that the child's interests be given primacy over the interests of the family unit as do certain other provincial statutes, such as British Columbia's Family and Child Services Act which states that the safety and well-being of the child shall be the paramount considerations.[162]

However, Alberta courts in interpreting the provisions of the Act regard the child's best interests as paramount as may be seen by Virtue, J.'s remarks in M. v. Dir. of Child Welfare:[163]

> I am satisfied that the learned trial judge acted properly in proceeding as he did upon the principle that the welfare of the child, S., was paramount. In seeking to determine whether blood transfusions were essential medical services in this case, he was applying the correct test under the Child Welfare Act.

In Re R.K., Russell, P.C.J. considered the factors enumerated in Section 2 in deciding to order a blood transfusion for an infant. She stated:[164]

> Finally, in considering the matters prescribed under Section 2 of the Child Welfare Act, while I am mindful that the preservation and privacy of this family would otherwise be preferred, I am satisfied having regard to the nature and degree of the risk involved, that the best interests of this child require that I do make an order of temporary guardianship. Given the parent's inability or unwillingness to make critical decisions concerning medical treatment, I am also satisfied that other less intrusive measures are not sufficient.

Thus, while these non-medical criteria must be considered by the decisionmaker, it is clear that the child's best interests must take precedence under the Act.

III. Administration of Treatment

A. Physicians' Duties

A doctor is under no legal duty to treat a patient, however, once he undertakes to do so, he owes a duty of care to the patient. One aspect of this duty - the doctor's duty of disclosure - has been discussed. Other components of the physician's duty of care include a "duty to attend, diagnose, refer, treat and instruct." 165 A failure to meet the standard of care involved in the discharge of any of these duties may lead to liability in negligence if the breach results in injury or harm to the patient.

1. The Duty to Refer (Consult)

The duty to "refer" means that the doctor is required to consult with another doctor(s) before administering treatment himself or refer the patient to another doctor.[166] This duty is particularly important in neonatology since neonatal medicine has been designed to provide the services of a wide array of pediatric specialists to deal with the myriad of problems that beset extremely premature and defective infants. Efficient transport systems permit the rapid transfer of these infants to neonatal intensive care units which are equipped with the technology needed to provide the specialized care that is required. Thus it is standard practice for high-risk infants to be transferred to the units. Appropriate cases for referral include those which the referring center lacks the equipment and expertise to provide the necessary care as well as those in which the diagnosis is uncertain. In Roystone v. Peninsula General Medical Center,[167] a doctor was found liable for the wrongful death of an infant since he had failed to refer the infant to a neonatal intensive care unit in the presence of respiratory distress at birth which was consistent with the symptoms of hyaline membrane disease.

Not all cases need to be referred to NICU's. For example, some infants who are extremely premature, or anencephalics cannot be currently helped by medical science. A referral in such cases would be pointless and would likely be refused by the neonatal unit. In assessing whether a duty to refer existed, the courts will be guided by prevailing medical practices, having regard to all the circumstances of the case.

Since neonatal units are composed of physicians who are highly specialized but whose knowledge is confined to a narrow sphere, the accepted practice within the units requires consultation among the various specialists before embarking on a course of treatment. The common law duty to consult will vary depending on the circumstances of a particular case. In certain cases, i.e., infants with minor defects or problems, a neonatologist may treat without consulting with other pediatric specialists but in complex cases, the duty to consult arises and the law will look unfavourably on physicians who fail to consult.

Ellen Picard in her book, Legal Liability of Doctors and Hospitals in Canada, states that the law does not provide an "absolute test" of when a doctor should consult, however she suggests that a duty to do so arises when:[168]

(i) the doctor is unable to diagnose the patient's condition;

(ii) the patient is not responding to the treatment given;

(iii) the patient needs treatment which the doctor is not competent to give;

(iv) the doctor has a duty to guard against his own inexperience (e.g., the student doctor); or

(v) the doctor cannot continue to treat the patient (e.g., while on vacation).

She also points out that "[t]he standards set by the courts in regard to the competence and division between specialties can only be as clear or as certain as the medical profession itself is on the matter." 169

A further obligation to consult is imposed by the C.M.A. Code of Ethics. The Code requires the physician to "recognize his limitations and, when indicated, recommend to the patient that additional opinions and services be obtained." 170 The Code also requires a doctor to "request the opinion of an appropriate confrere acceptable to the patient when diagnosis or treatment is difficult or obscure, or when the patient requests it", 171 and when another doctor requests his opinion, that he "report in detail his findings and recommendations to the attending physician". 172

Hospital bylaws may also require a physician to consult in certain cases. [173] For example the medical staff bylaws of the Foothills Hospital in Calgary have adopted the C.M.A.'s Code of Ethics and state that the Code "shall govern the professional conduct of members of the medical staff." [174] In addition, the Hospital's 'Rules and Regulations' provide that a Department Director (Head of Pediatrics) or Division Chief (Head of NICU) "may" require a physician in his department or division to obtain a consultation when: [175]

> (i) the diagnosis of the patient is in doubt after reasonable investigation;
>
> (ii) the patient does not appear to be responding to the prescribed treatment;
>
> (iii) the patient's condition is serious enough to consider life to be threatened;
>
> (iv) there are other circumstances which in the opinion of the Department Director or Division Chief require a consultation.

The Regulations further provide that: [176]

> a consultation shall be obtained by the responsible physician when required by government policy or law, Hospital Bylaws, Medical Staff Bylaws, departmental policy as approved by the Medical Advisory Committee.

2. The Duty to Treat

A doctor has the right to refuse to accept an infant as a patient, however, once he accepts an infant as a patient he has a duty to provide treatment to that infant.[177] He may not arbitrarily refuse to treat an infant when the parents want to continue the infant's treatment. Parents have the right to "consent" to the initiation of their child's treatment as well as the right to decide to "continue" treatment.

The C.M.A. Code of Ethics requires the physician "when he has accepted responsibility for an acutely ill patient, [t]o continue to provide his services until they are no longer required or until he has arranged the services of another suitable physician."[178] The Code further provides that the physician must "recognize that the patient has the right to accept or reject ... any medical care recommended to him."[179] Refusal to provide or to continue treating an infant against the parent's wishes may therefore subject the physician to disciplinary action by the College of Physicians and Surgeons.

A physician's unwarranted refusal to treat an infant is also a breach of certain duties imposed upon him by the criminal law. Section 217 provides that everyone who undertakes to do an act is under a legal duty to do so if omitting to do so would endanger a person's life, while Section 218 imposes liability on everyone who unlawfully abandons a child under ten years, so that its life or health is likely to be endangered.

A breach of the duty imposed by Section 217 of the Criminal Code may result in a finding of criminal negligence [180] against the physician, and if death ensues, constitutes culpable homicide.[181]

The preceding discussion applies to a situation in which a physician arbitrarily refuses to provide medical treatment to an infant over the parents' objections. However, the law does not leave the physician without recourse if he believes that further treatment is not in an infant's best interests. In such cases, the physician can invoke the parens patriae jurisdiction of the courts or he may apply to child welfare authorities to obtain authorization to withdraw treatment.

Finally, if the parents are unable or unavailable to render a decision, the physician may discontinue treatment if he believes it to be in the infant's best interest. Magnet has suggested that in such cases it would be wise for the doctor to consult with an ethics committee or obtain prior court approval before ceasing treatment. Although the doctor is not required to do so, this practice would lend support to the assertion that the doctor acted in good faith and with due care in the event the decision is later challenged.[182]

B. Liability for Breach of a Physician's Duties

A physician who breaches the duty of care which is owed to a patient may be disciplined by the hospital in which he has privileges and by the College of Physicians and Surgeons in addition to possible criminal prosecution or civil liability by way of damages.

In Canada, the criminal law has little impact on the practice of medicine. Criminal prosecutions of physicians are extremely rare. It has been suggested that the reason for this is "because the type of harm contemplated in the administration of treatment is not of the degree to warrant the intervention of the criminal law".[183] Nonetheless, the possibility of prosecution does exist in a sufficiently serious case.[184]

Damages awarded in civil actions for the death of infants due to negligence are minimal and this fact limits the usefulness of the civil action as a mechanism for controlling inappropriate medical conduct in neonatal medicine. Parents may only claim for their pecuniary losses; the law does not permit any claims for loss based on their affection and love for the child.[185] Generally, the courts have dismissed parental claims of probable pecuniary benefits as mere speculative possibilities when their children are very young.[186]

In Alberta, parents may bring an action under the Fatal Accidents Act[187] in respect of the death of their infant but the Act limits the damages that the parents may recover for the death of their child to $3,000.00.

Parents may be entitled to recover punitive or exemplary damages when a doctor's conduct may be considered outrageous, malicious or contemptuous. Punitive damages are non-compensatory damages which are awarded to punish the defendant and to act as a deterrent to others.

Although punitive damages are not generally awarded in negligence cases, the British Columbia Supreme

Court held that exemplary damages would be permitted in a negligence case where the defendant's conduct in denying the plaintiff appropriate medical treatment could be described as: [188]

> high-handed, arrogant, ... displaying a reckless disregard for the rights of the plaintiff. ... showed a callous disregard for his feelings ... and ignored the dictates of common decency as well as commonsense.

Sanctions may also be imposed upon the physician by the hospital in which the physician has privileges as well as disciplinary action being taken by the College of Physicians and Surgeons. For example, the medical staff bylaws of the Foothills Hospital provide that a medical staff member who contravenes the provisions of medical staff bylaws or rules and regulations is subject to immediate temporary suspension of all his or her staff privileges by the Division Chief prior to a hearing. [189]

Breach of hospital bylaws or a failure to comply with the duty of care (adequate disclosure, duties to consult, refer or treat) may also be considered to be "unbecoming conduct" [190] or "displaying lack of skill or judgment" [191] according to the provisions of the Medical Professions Act. Section 34(2) of the Act provides

> Any matter, conduct or thing that in the judgment of the investigating committee, the council or the Court of Appeal, is such as to be inimical to the best interests of the public or the profession whether or not the act or conduct is disgraceful or dishonourable, is unbecoming conduct on the part of a registered practitioner.

This definition of unbecoming conduct is broad enough to cover inadequate or misleading presentation of information, applying undue pressure on parents, failing to refer or consult and unwarranted refusals to treat or to continue treatment of seriously ill or defective infants.

When a registered practitioner is found guilty of unbecoming conduct, the council may reprimand the physician, impose conditions or restrictions on the physician's registration, suspend him for a period of up to three years or order the physician's name to be struck off the register.[192] In addition to the preceding penalties, the College may order the physician to pay the costs of the investigation as well as imposing fines of not more than $1,000 for each allegation proven against the physician.[193]

As may be surmised, sanctions imposed by the hospital or the College of Physicians and Surgeons are a more effective means of controlling unacceptable behavior on the part of physicians than the courts. The College and the hospital will conduct their own investigations and the physician's conduct will be reviewed and evaluated by his peers. Disciplinary action can be taken immediately, i.e., immediate suspension of hospital privileges, and the threat of removal from the Rolls is a more effective deterrent than the relatively small damages that may be awarded in a civil action.

IV. Withdrawing Treatment - Passive Euthanasia

A. Patient's Right to Refuse Treatment

This section of the paper will focus on the question of when parents and other surrogate decisonmakers may lawfully decline continued life-sustaining treatment on behalf of infants and other incompetent patients. The writer will first examine American jurisprudence on this issue followed by a review of the relevant Anglo-Canadian caselaw.

B. The U.S. Experience

For more than a decade American courts have been confronted with the perplexing issues arising from the termination of medical treatment in difficult and hopeless cases. The courts have responded by clarifying the rights of incompetent patients and by attempting to formulate procedural guidelines under which surrogate decisionmakers and medical personnel can allow natural death by the cessation of treatment.

For the purposes of analysis the cases may be classified into three broad categories: (1) cases in which the patient is permanently comatose; (2) cases in which treatment is withheld due to the quality of life possible for the patient; and (3) cases in which it is unclear whether providing further treatment is in a patient's best interests.

1. The Permanently Comatose Patient

The highly publicized decision of the New Jersey Supreme Court in In Re Quinlan,[194] was the subject of considerable debate. For reasons that were not entirely clear, Karen Quinlan, then twenty-one, stopped breathing for at least two fifteen-minute periods. As a result, she suffered brain damage to such an extent that medical experts characterized her condition as being in a "chronic, persistent vegetative state."[195] Ms. Quinlan did not, however, meet the criteria of whole "brain death" as determined by the Ad Hoc Committee of the Harvard Medical School. She was therefore considered to be "alive" by prevailing medical and legal standards.[196] Nevertheless, medical experts agreed that there was no reasonable possibility that she would ever be restored to a cognitive or sapient life.[197] Her breathing was sustained by a respirator and the prevailing consensus at the time was that she could not survive without it.

Karen's father petitioned the court to be appointed her guardian and sought the power to authorize the disconnection of the respirator, while her physicians objected to the removal of the respirator, on the basis that it would be contrary to accepted medical practice.[198]

In a unanimous opinion, the New Jersey Supreme Court extended the constitutional right of privacy which had been recognized by the United States Supreme Court in earlier decisions. The Court stated:[199]

> Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances ...

In balancing the state's interest in the preservation of life against Karen's right of privacy, the Court found the state could not demonstrate any "compelling interest" which would justify interfering with Karen's right. Her prognosis was very poor and aggressive and invasive treatment was required to maintain her which led the Court to conclude: 200

> We think that the State's interest _contra_ weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest.

Having decided that Karen herself had the right to refuse further treatment, the Court concluded that her right should not be denied simply because she was unable to exercise it for herself. Therefore her father (as guardian) and the rest of her family would be permitted "to render their best judgment ... as to whether _she_ would exercise it in these circumstances." 201

The Court emphasized that their decision should be the decision that would have been made by Karen herself. This subjective approach is known as the doctrine of 'substituted judgment'. An alternative test which the court could have used is the "best interests" test which would require the decisionmaker to make an objective assessment as to what a reasonable person in Karen's position would have decided. In this case, although the court surmised that most people would in Karen's circumstances exercise a choice to refuse further treatment, the operative criterion in making the decision was what Karen _herself_ would have chosen.

While recognizing that withdrawal of the respirator would violate current standards of medical practice Hughes, C.J. reasoned: [202]

> Determinations as to these must, in the ultimate, be responsive not only to the concepts of medicine but also to the common moral judgment of the community at large.

Under the circumstances of this case (the hopeless loss of cognitive or sapient life) the decision to refuse treatment would, he believed, be acceptable to society. [203]

Since _Quinlan_, a number of other state courts have addressed the issue of withholding further treatment from permanently comatose patients in persistent vegetative states. [204] In each of these cases, the courts have followed the reasoning in the _Quinlan_ decision, holding that state interests in the preservation of life are not sufficiently compelling to overcome an unconscious person's right to prevent unwanted treatments through a substituted judgment on his behalf.

Although the court in Quinlan based its decision on a constitutional right of privacy, other state courts have found an alternative basis for the exercise of the right to refuse treatment supported by the common law right to self-determination. [205]

Quinlan and the cases which have followed concerned comatose adults. However, there is no reason to suppose that a comatose infant would not be accorded the same right to surrogate refusal of further life-saving treatment. [206]

Apart from common law doctrine and constitutional theory, one state, Louisiana, has adopted legislation which specifically authorizes withdrawal of further medical treatment from infants in an irreversible coma. The Louisiana statute prohibits the denial of food, water or oxygen from an infant with the intention of permitting or causing the infant's death for any reason and it further prohibits the denial of medical or surgical care necessary to attempt to save the life of a disabled child. However, an exception is made which allows parents and physicians to discontinue further treatment where competent medical judgment has concluded there is no reasonable chance of recovery from a "continual, profound, comatose state."[207] In a recent decision, the Louisiana Supreme Court upheld the constitutionality of the statute, stating:[208]

> Modern medical science has developed procedures and devices which assist, supplement and even replace basic bodily functions. ... In this perspective we note a vast difference between a person whose quality of life has been significantly decreased by a devastating illness or injury and a person whose comatose body has been significantly (and perhaps unwarrantedly) invaded by machines which cannot cure or improve, but can only artifically prolong an existence that will never be known by the patient. These extraordinary means of preserving a person's "existence" in a vegetative coma have little to do with the continuation or ending of life, and removal of such systems under highly restricted circumstances cannot reasonably be construed as violative of the constitutional prohibition against euthanasia. Indeed the law under review is a warranted exception to the prohibitory rules in Part XIX which were designed to implement the constitutional protection against euthanasia when the child is unwanted or the quality of his life will be substantially diminished.

Thus, a consensus appears to have been reached in the United States that a permanently comatose individual's right to refuse life-saving medical treatment will, on balance, override the state's interest in the preservation of life.

2. Poor Quality of Life

(a) Terminal Illness

In Superintendent of Belchertown State School v. Saikewicz,[209] the Supreme Judicial Court of Massachusetts was asked to review the decision of the Probate Court which had followed the recommendation of a guardian *ad litem* that not treating the resident of a state hospital would be in the patient's best interests.

The case involved a profoundly retarded, sixty-seven year old man who had developed leukemia. Joseph Saikewicz had an I.Q. of 10 and a mental age of approximately 2 years and eight months. He was unable to communicate verbally and was, apart from his disease, in generally good health.

Chemotherapy, the recommended treatment offered only a 30-40 percent chance for remission which could last anywhere from 2 to 13 months, but would not cure the leukemia. It caused severe adverse side-effects ranging from severe anemia involving bleeding and potentially fatal infections as well as "severe nausea, bladder irritation, numbness and tingling of the extremities and loss of hair."[210]

If no treatment was given death would occur within a matter of weeks, or possibly a few months. The disease itself would cause no pain nor would the eventual death be painful.

The Saikewicz Court, following the Quinlan Court's lead, found a constitutional right of privacy broad enough to encompass the right of a competent patient to refuse treatment. This right, the Court concluded, must extend to the incompetent patient as well, "because the value of human dignity extends to both." [211]

The Court next determined the considerations that must form a part of the decisionmaking process. Noting that the state had the responsibility to protect the "best interests" of the incompetent person in its role as parens patriae, it recommended that a flexible approach be taken in determining the incompetent's best interests.

Following Quinlan, the Court adopted the substituted judgment standard, requiring that insofar as possible the guardian must determine what the actual desires of the incompetent person might be. Thus, although most people suffering from leukemia choose the chemotherapy in spite of its side-effects, the Court ruled that withholding this treatment would be in Mr. Saikewicz's best interests, for unlike the competent person who would understand the reason for the pain, Saikewicz would be "involuntarily immersed in a state of painful suffering", for reasons he would not understand. Since most people would not choose to undergo great pain for reasons they could not comprehend, the Court concluded that Saikewicz himself would have refused the chemotherapy if he were miraculously competent for a moment, knowing that he would immediately be returning to his uncomprehending, incompetent state.

In making a substituted judgment, the Court emphasized that while "the primary test is subjective in nature", an objective viewpoint similar to the "reasonable person" test is a subordinate component as well.[212]

Liacos, J. recognized that attempting to apply the subjective substituted judgment test would be more difficult in some cases than in others. Citing the Quinlan case as an example, he commented that it would be fairly easy in cases like Karen's where her father could rely on his knowledge of her views and wishes in the past, while Joseph Saikewicz was profoundly retarded and uncommunicative throughout his whole life. In these difficult cases, he stated:[213]

> While it may thus be necessary to rely to a greater degree on objective criteria, such as the supposed inability of profoundly retarded persons to conceptualize or fear death, the effort to bring the substituted judgment into step with the values and desires of the affected individual must not, and need not, be abandoned.

The Court expressly rejected any implication being drawn which would equate "the value of life with any measure of the quality of life."[214] The judges stressed that Saikewicz's mental retardation "had no place" in their decision. Instead, the "quality of life" they referred to had to do with "the continuing state of pain and disorientation" caused by the chemotherapy. This aspect of their decision has been criticized. Magnet and Kluge argue that while the Court explicitly disavows basing its decision on the quality of Saikewicz's life, it "tolerates pure quality of life factors in the decisional balance" by rejecting a continued life of intolerable suffering.[215] Their point is correct, but the Court carefully circumscribes the limits of this decision holding that:[216]

> The interest of the state in prolonging a life must be reconciled with the interest of an individual to reject the traumatic cost of that prolongation. There is a substantial distinction in the state's insistence that human life be saved where the infliction is

> curable, as opposed to the state interest where, as here, the issue is not whether but when, for how long, and at what cost to the individual that life may be briefly extended. (emphasis added).

Saikewicz thus stands for the proposition that painful treatments which offer no possibility of a cure and which can only prolong the process of dying may be withheld in the terminal stages of an incurable mortal illness.

The principles enunciated in Saikewicz were later explained and amplified by the Massachusetts Court of Appeal in two decisions involving the withdrawal of treatment from patients suffering from terminal illnesses. In Matter of Dinnerstein,[217] the Appeal Court upheld the decision of the physician and family not to resuscitate an elderly woman dying of Alzheimer's disease. Medical evidence showed that the case was hopeless; the patient would soon die and efforts at resuscitation would neither "cure or relieve" her from certain death. Following the Massachusetts Supreme Judicial Court's reasoning in Saikewicz, the Appeals Court submitted:[218]

> that, when the court spoke of life-saving or life-prolonging

> treatments, it referred to treatments administered for the purpose, and with some reasonable expectation of effecting a permanent or temporary cure of or relief from the illness or condition being treated. 'Prolongation of life', as used in the Saikewicz case, does not mean a mere suspension of the act of dying, but contemplates, at the very least, a remission of symptoms enabling a return towards a normal, functioning, integrated existence.

When treatment provided no hope of restoration the family and physician were entitled to withdraw further life-prolonging treatment. Subsequently, in Matter of Spring,[219] the Massachusetts Court of Appeal permitted the termination of hemodialysis treatment from an elderly patient who suffered from dementia and a total, irreversible loss of kidney function. Mr. Spring resisted the dialysis by pulling the tube out and kicking the nurses. Without dialysis he would die within a month but the dialysis did nothing to correct or improve his underlying condition and further deterioration of his physical and mental state was expected. The Court found that the patient, if competent, would have wished to discontinue the dialysis since his life was "essentially behind him, he was not a suitable case for a kidney transplant and that the remainder of his days would be spent in an irreversible state of dementia".[220] Given these factors, in addition to the fact that his physician supported the family's view that treatment should be withdrawn, the court held that the state's interest in the preservation of life was insufficient to warrant intervention in the nontreatment decision.

The preceding principles would similarly apply in the case of an infant suffering from an incurable terminal illness. In Custody of a Minor,[221] a four month old infant was diagnosed as suffering from cyanotic heart disease which at the time was considered to be incorrectable (recently some of these infants have received heart transplants which have been successful). Death would normally occur within the infant's first year of life with or without treatment. The Court was asked to uphold a juvenile court order which had authorized a "No Code" order being placed on the infant's medical chart which would preclude "heroic" resuscitation efforts being made if the infant were to suffer from respiratory or cardiac arrest. In the absence of a "No Code" order, treatment would consist of "intercardial injection of ... drugs, intercardial heart massage, or electric shock treatment."[222] Physicians testified that these treatments would be "invasive and traumatic", could result in brain and liver damage and substantial pain, further weakening the infant and moreover, that such treatment would violate current medical ethics.

The Court compared the case to that of an incompetent, terminally ill adult, observing that "both cases raise the issue whether and by what means a person has the right to refuse the invasion of his or her bodily integrity by refusing extraordinary medical treatment." 223

Following the approach it had enunciated in Saikewicz, the Massachusetts Supreme Judicial Court utilized the substituted judgment test basing its decision on what the child's wishes would have been. In upholding the "No Code" order, the Court concluded: 224

> ... if this child 'had the mental capacity to understand the incurable nature of his illness, the terminal prognosis, the nature and purpose of a full no-code order and the virtual certainty of its limited and temporary effect, he would choose to forego its use.'

As in the preceding cases, the Court's holding was based upon narrow grounds, namely the invasive nature of the treatment, the pain and suffering caused by the treatment and the virtual impossibility of the treatment effecting a cure of the infant's underlying terminal condition. However, another state court has followed a different course than adopted in the Saikewicz case. The

New York Court of Appeals was presented in Matter of Storar,[225] with a fact situation almost identical to that in Saikewicz.

John Storar was a profoundly retarded fifty-two year old man with a mental age of approximately 18 months. He too had resided in a state facility since early childhood and was diagnosed as suffering from an incurable bladder cancer which caused him to lose blood. His life expectancy was estimated to be between 3 and 6 months although this period could be shortened from the loss of blood.

Mr. Storar disliked receiving the transfusions and was also distressed by the blood and blood clots which appeared in his urine after a transfusion. Because of this, his mother (who was his guardian) withdrew her consent to further transfusions. Following her refusal, the director of the facility petitioned the court for authorization to continue the transfusions. The Court held that the application to discontinue the transfusions should have been denied.

In analyzing the applicable principles governing this type of case the New York Court drew a distinction between cases involving previously competent patients and patients like John Storar who had never been competent. Profoundly retarded individuals had the same mental capacities as infants and their rights were to be governed by the same principles which applied with respect to infants. In such cases, the Court rejected the application of the "substituted judgment" doctrine which was applicable in the case of previously competent patients, stating,[226]

> ... it is unrealistic to attempt to determine whether [they] would want to continue potentially life-prolonging treatment if [they] were competent ... that would be similar to asking whether 'if it snowed all summer would it then be winter?'

Thus, the fact that John Storar disliked the transfusions was irrelevant, since that was to "be expected of one with an infant's mentality."[227]

The Court found that there were two threats to John Storar's life. He could die of cancer of the bladder or he could die from "loss of blood which posed the risk of an earlier death, but which ... could be replaced by transfusions."[228] Nevertheless, the Court took the position that the transfusions constituted the only life-saving treatment available for John Storar and concluded that[229]

> the courts may not permit a parent to deny a child all treatment for a condition which threatens his life. ...[and] should not ... allow an incompetent patient to bleed to death because someone, even someone as close as a parent or sibling, feels that this is best for one with an incurable disease.

On the surface it appears that the Court adopted a sanctity of life position, but in fact, the majority were apparently moved by quality of life considerations, finding that "the transfusions did not involve excessive pain and that without them his mental and physical abilities would not be maintained at the usual level." [230] However, with the transfusions his quality of life would remain the same, although he would ultimately succumb to the cancer.

The decision has been criticized for its lack of legal analysis. The New York Court did not discuss the right to privacy or self-determination nor did it give any indication of an alternative test (to replace the substituted judgment test) which could be used by a surrogate decisionmaker to refuse medical treatment for an incompetent or an infant. [231] Thus, it implies that incompetent patients must always be given treatment whenever life prolonging treatment is available.

This decision runs counter to the majority of decisions handed down by American courts which have permitted the withdrawal of painful, life-prolonging treatment in terminal cases involving incompetents where such treatment cannot cure or alleviate the underlying condition.[232]

These decisions have permitted the withdrawal of treatment in cases in which the patient has only a few weeks or months left to live. However, it is unclear what length of life remaining would justify a refusal of treatment in the case of a seriously ill infant. For example, there are a number of diseases which may be detected in infancy, such as Tay Sachs disease, metachromatic leukodystrophy, sickle-cell disease and Werdnig-Hoffmans disease which are currently untreatable and will lead to death in early childhood, although the child may live for a few years. American courts have not yet addressed the issues of how imminent death must be for treatment to be withheld or whether aggressive treatment should be directed at complications of the terminal disease or other intervening illnesses.

(b) The Seriously Ill or Defective Infant Who is Neither Comatose nor Terminally Ill

American courts have considered a number of cases in which parents have withdrawn their consent to life-saving treatment from seriously ill or defective infants who are neither comatose or terminally ill.

In deciding whether parental treatment/ nontreatment choices should be upheld or overruled, the courts have sought to balance the competing and often conflicting interests of the child, the parents and the state.

The child's interests include a right to privacy and bodily integrity. These rights include a right to refuse medical treatment under certain circumstances and must be exercised for the child by a surrogate.

Parents are generally empowered with the right to make medical decisions regarding their child which corresponds with their duty to provide their child with necessary medical care. Parental rights to make decisions for their children are based upon "the common law assumption that parents have the greatest possible interest in the physical and emotional well-being of their children." [233] American law also recognizes a right of privacy which exists with respect to family life - including the right to marriage, procreation, motherhood, child rearing and education. [234] The right to rear children without state interference has been given strong judicial expression in a number of decisions upholding parents' rights to determine their children's religious upbringing and to direct their education. [235] In the landmark decision of Prince v. Massachusetts, the United States Supreme Court upheld the doctrine of parental automony stating: [236]

> It is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder.

However, parental authority is not absolute. For although in theory, parents will make medical decisions which will advance the best interests of the child, in practice parents' medical decisions regarding medical treatment for their child may be influenced by their own interests which may conflict with the child's. Because of the possible conflict between parental interests and those of the child, the right of parents to make medical decisions for their children is not unlimited. In Prince, the court observed that parents did not have the "liberty to expose the community or the child to communicable disease or the latter to ill health or death." 237

The state, as parens patriae, has an obligation to intervene in such cases to safeguard the child's heath and well-being because of the state's fundamental interest in the preservation of life.

In seeking to strike a balance between these various interests American courts will look at several relevant factors before considering intervention and possible overruling of a parental choice: 238

> The state should examine the seriousness of the harm the child is suffering or the substantial likelihood that he will suffer serious harm; the evaluation of the treatment by the medical profession, the risks involved in medically treating the child ... the underlying consideration is the child's welfare and whether his best interests will be served by medical treatment.

Some broad general guidelines have emerged from the courts' decisions. Generally, if the child's life is in danger, parents must consent to the necessary treatment. In Custody of a Minor, 239 (the Chad Green case) the parents of a twenty-month old child suffering from acute lymphocytic leukemia refused to consent to chemotherapy which was the only known medically effective treatment. Chemotherapy in this case, unlike the Saikewicz case, offered "a substantial hope of cure." Expert testimony presented surmised that if the disease were left untreated, death would ensue within six months.

Upon balancing the parent's rights, the child's interest and the state's interest, the Court had no hesitation in deciding that state intervention was appropriate when necessary to save the child's life.

In discussing the parent's rights, the Court stated: 240

> ... where a child's well-being is placed in issue, 'it is not the rights of the parents that are chiefly to be considered. The first and paramount duty is to consult the welfare of the child'.

Hennessey, J. found chemotherapy to be in the child's best interests because of the possibility it offered a cure, since there was no other effective alternative, and the adverse effects were minimal when compared to the immense benefits offered by the treatment. The child's inability to understand the reason for the treatment and the temporary pain involved with the treatment could not outweigh his long-term interest in a long and healthy life.

The Court also discussed the test to be used to ascertain the interests of the child, and concluded: [241]

> In a care like this one, involving a child who is incompetent by reason of his tender years, we think that the substituted judgment doctrine is consistent with the "best interests of the child" test ... the best interests analysis like that of the substituted judgment doctrine, requires a court to focus on the various factors unique to the situation of the individual for whom it must act. As a practical matter, the criteria to be examined and the basic applicable reasoning are the same.

Finally, the Court identified three state interests which supported the decision to order treatment over the parent's objections: (1) The state's interest in protecting the welfare of children, (2) the state's interest in the preservation of life, and (3) the state's interest in maintaining the ethical integrity of the medical profession. Since the chemotherapy offered Chad Green a chance at survival as opposed to merely prolonging his dying, the Court held that the state's interest in preservation of life applied "with full force" superceding parental prerogatives.

Chad Green had the chance with medical treatment to have a normal, healthy life. However the courts have also ordered medical treatment over parental refusals in cases in which the child's future developmental prospects may be considered relatively poor. In Application of Cicero,[242] the father withdrew his consent for the surgical repair of his infant daughter's meningomyelocele when he learned of the potential handicaps she would suffer. The court appointed a guardian to consent to the surgery finding that without treatment the infant would likely die. Mr. Justice Stecher stated:[243]

> This is not a case where the court is asked to preserve an existence which cannot be a life. What is asked is that a child born with handicaps be given a reasonable opportunity to live, to grow and hopefully to surmount those handicaps ... where, as here, a child has a reasonable chance to live a useful, fulfilled life the court will not permit parental inaction to deny that chance.

Two years later a Florida court reached a similar conclusion and overrode a Florida couple's refusal to consent to surgical or any other form of treatment for their infant daughter who was born with spina bifida.[244] Elin Daniels suffered from a potentially more disabling form of spina bifida than did the infant in Cicero. She had several of the clinical criteria cited by Lorber as indicators for selective nontreatment. All of the physicians who examined her agreed that without the surgery the chances for mental retardation increased as did the possibility of a life-threatening infection. Although the court was presented with conflicting testimony (two doctors recommended that surgery be performed as soon as possible while two other doctors did not recommend surgery) the judge ruled in favour of the surgery on the basis that parents do not have the right to refuse potentially life-saving treatment for their child. 245

A few months prior to the Daniels case, Siamese twins were born in Danville, Illinois.[246] The infants, Jeff and Scott Mueller were joined below the waist sharing a common digestive tract and three legs. They suffered from respiratory distress and were in critical condition. The attending obstetrician ordered that the infants not be resuscitated, and the father, a physician who was present at the delivery, agreed.

The infants were moved to the nursery and an order that they were to be given no food or water in accordance with the parent's wishes was written on their chart. An anonymous complaint regarding the infants' treatment led to an investigation and a petition of neglect being filed against the parents and culminated in a judicial finding that the infants had been neglected. Temporary custody was given to the family services agency and the infants were transferred over the parents' objections to a Chicago hospital for evaluation and treatment.

The following month, the Muellers and the attending physician were charged with attempted murder and 13 other charges to which they pleaded not guilty.[247] It marked the first time in United States history that criminal charges had been filed against parents or a physician for withholding food and medical treatment from an infant with congenital defects. However, the charges were later dropped for lack of evidence, due in part to the inability or unwillingness of the nurses who testified to link either the parents or the physician to the order to withhold food from the infants.[248]

In the months which followed the twins were returned to their parents. Medical studies revealed that the infants would not survive surgical separation and that they were expected to live for no more than a few months during which time they would require continuous nursing care. [249]

Another earlier case, Maine Medical Centre v. Houle, [250] reveals the extent to which some American courts are prepared to go to protect the lives of seriously defective infants. A medical examination revealed that the infant had no left eye, had a rudimentary left ear with no ear canal, a malformed left thumb and a tracheal esophageal fistula which prevented the ingestion of food allowing fluid to enter the infant's lungs leading to pneumonia and other complications. [251] The father refused consent to the medically recommended surgical repair and ordered the intravenous feeding to be stopped. A temporary restraining order authorizing the continuance of intravenous feeding was obtained by the doctor pending a hearing regarding the proposed surgery.

Within days the hearing was held. The child's condition had deteriorated and further medical investigation revealed other abnormalities as well as "the virtual certainty of brain damage from anoxia."[252] This finding apparently caused the attending physician to change his opinion and at the hearing he recommended against the surgery and other life supporting measures.

The Court overruled views of both the attending physician and the father and directed a guardian ad litem to consent to the surgery as well as any other required treatments. Mr. Justice Roberts commented in ordering the surgery:[253]

> ... at the moment of live birth there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life itself ... The measures proposed in this case are not in any sense heroic measures except for the doctor's opinion that probable brain damage has rendered life not worth preserving ... However, the doctor's qualitative evaluation of the value of the life to be preserved is not legally within the scope of his expertise the issue before the court is not the quality of the life to be preserved, but the medical feasibility of the proposed treatment compared with the risk of almost certain death should treatment be withheld. Being satisfied that corrective surgery is medically necessary and medically feasible, the court finds that the defendants herein have no right to withhold such treatment and that to do so constitutes neglect in the legal sense.

Mr. Justice Roberts did point out however that, if medical opinion was that the infant's life could not be preserved, then heroic measures did not have to be taken.

The decision stands for the proposition that where medical treatment is feasible and can be undertaken with less risk to the child's life than the underlying defect, then treatment should be given. It also holds that brain damage is not a valid reason to deny treatment. Mr. Justice Robert's decision has been said to be a decision per incuriam and has been criticized as being a "knee-jerk reaction to the proposition that life is to be sanctified at all costs."[254] This may be a correct interpretation given the apparent severity of the infant's defects (the child died before the surgery could be carried out). However, the Houle case as well as the Mueller and Daniels cases, exemplify the tendency of American courts to be extremely protective of "infant" human life no matter what its quality, in the exercise of their parens patriae jurisdiction.

While most American courts have been prepared to intervene to protect and preserve the lives of defective infants in need of treatment, a few courts have upheld parental nontreatment decisions. The Phillip Becker case involved a 12 year old boy with Down's Syndrome whose parents refused to consent to surgery to repair a congenital heart defect.[255] Without the surgery, damage to his lungs would result in a progressive loss of energy leading to severe incapacitation and ultimately to his death. With the surgery, his lifespan would be significantly increased. Phillip's doctor recommended that the surgery be performed.

In upholding the parents' decision to deny the surgery, the Court first examined the constitutionally protected right of parental autonomy which allows parents the right to raise their children as they think best. However, parental choice must be balanced against the state's duty as *parens patriae* to protect children and the state's interest in the preservation of life. The Court emphasized that normally the state should defer to the wishes of the parents, stating, "it has a serious burden of justification before abridging parental autonomy by substituting its judgment for that of the parents."[256]

The underlying consideration in the Court's view was whether medical treatment would serve the child's "best interests".

Medical evidence presented showed that there was a 5-10% risk of mortality from the surgery. In Phillip's case, the risk would be somewhat greater due to the pulmonary vascular changes which had already occurred as well as the Down's Syndrome which was associated with greater post-operative complications. [257] Based upon these factors, Caldecott, J. refused to overrule the parents' decision to withhold the surgery.

The Becker decision has been widely criticized for giving undue weight to parental autonomy and by an interpretation of Phillip's "best interests" in a manner that was not supported by the facts. Phillip was doomed to die a slow, agonizing and early death without treatment compared to a healthy, normal life with treatment. Many legal commentators have suggested that the case was wrongly decided and unlikely to be followed by other courts. [258]

Three years after the Becker case, a nationwide controversy errupted over the case of a Down's Syndrome infant who was born with an esophagael atresia whose parents refused to consent to surgery to remove the blockage. The case, known as the 'Baby Doe' case, resulted in the passage of detailed government regulations mandating that medical treatment be given to handicapped infants.[259]

An Indiana county court and the Indiana Supreme Court declined to overrule the parent's refusal and the infant died six days after its birth. Indiana courts subsequently refused to reconsider the case because it is moot. Since the Indiana Supreme Court sealed the records of the case it is impossible to know the basis of the Court's decision. Furthermore, it is not known whether the infant suffered from additional defects apart from the atresia which may have resulted in a medical assessment that surgery was contraindicated. However, the commentary surrounding the case has been based on the assumption that the atresia was the only medical defect the infant had, apart from the presence of Down's Syndrome.[260] If this is correct, the Infant Doe case is not consistent with the developing body of American caselaw which restricts parental rights to refuse life-saving medical treatment on behalf of their handicapped children.

Apart from these decisions, the courts have also respected parental discretion where alternative medical treatments are available. In Matter of Hofbauer,[261] the parents had chosen to treat their young son with Hodgkin's disease with nutritional therapy including injections of laetrile instead of chemotherapy. After hearing conflicting medical testimony regarding the advantages and disadvantages of each mode of treatment, the Court stated: [262]

> ... the issue for our determination is not which is the better treatment. Nor is it which method we or someone else would select under similar circumstances ... The primary right, duty and privilege to select the type of medical care to be given and the physician to administer it belongs to the parent.

Medical opinion conflicted regarding the relative efficacy of each method of treatment, and the parents expressed willingness to adopt the more conventional chemotherapy if the attending physician so recommended. The Court refused to overrule the parents choice of treatment.

The New York Supreme Court considered the issue of parental choice again in Weber v. Stony Brook Hospital. [263] This case, known as the 'Baby Jane Doe' case involved an infant born with multiple serious disorders, including myelomeningocele, microcephaly and hydrocephalus. The parents after consulting with neurological experts, nurses, religious counsellors and a social worker elected to adopt a conservative form of treatment instead of the surgery proposed by the hospital.

Two medical experts testified that the parents' choice of a conservative form of medical treatment "was well within accepted medical standards" and the court found medical records in evidence supported this view; for although the mortality rate was higher with the conservative therapy, the surgery increased the risk of the infant's losing any remaining leg function and would result in an increased propensity to kidney infections and other disorders.

The Court upheld the parents' choice of treatment, pointing out that:[264]

> It is manifest, therefore, that this is not a case where an infant is being deprived of medical treatment to achieve a quick and supposedly merciful death. Rather it is a situation where the parents have chosen one course of appropriate medical treatment over another. These concededly concerned and loving parents have made an informed, intelligent and reasonable determination based upon and supported by responsible medical authority. On this record, and in light of all the surrounding circumstances, we find that the parent's determination to be in the

> best interest of the infant. Accordingly, there is no basis for judicial intervention.

In each of the preceding cases, the courts have rendered a decision upholding or reversing a parental decision to withhold medical treatment based upon a determination being made of whether continued life is in the best interests of the incompetent or the child. Several conclusions can be drawn from the decided body of cases thusfar.

Parents may not deny life-saving medical treatment to their child when treatment can restore the child to a normal, healthy life.[265] In cases where life-saving treatment is possible, although the child will remain handicapped, the answer is less clear. But, where the child will suffer from a mild to moderate handicap as in most cases of spina bifida and Down's Syndrome (where multiple congenital abnormalities are not involved) treatment will usually be ordered.[266] Even in cases where the child's potential for future development is uncertain or questionable, the courts have overruled parental refusals.[267]

Nonetheless, the courts have evinced a willingness to allow parental discretion to prevail where the parents choose a medically recognized course of treatment from a range of alternatives, for example, they may choose a conservative treatment. However, they may not reject all forms of treatment if the purpose of such a refusal is to result in the infant's death. [268]

American case law suggests that parental discretion to refuse life-saving medical treatment for seriously defective newborns is narrowly circumscribed. Parental refusals of medical treatment for their children will be upheld when such treatment merely prolongs the dying process or subjects the child to a life of intolerable pain. Parents may also withhold treatment from infants who are permanently comatose with no chance for a cognitive, sapient existence. [269]

Very few infants requiring neonatal care would meet these criteria. In the vast majority of cases, medical treatment which would enable a child an opportunity for continued life is clearly in the infant's best interests and the courts will not permit parents or a surrogate decisionmaker to deny a child this chance.

3. Uncertain Cases

Beyond these two groups of cases in which nontreatment and treatment are clearly mandated lies a third group of cases in which it is not clear whether life-sustaining medical treatment is in the infant's best interests. Infants within this category comprise a significant number of the cases which are found in neonatal intensive care units. The most common examples of cases within this group as discussed in Chapter One are premature or low-birth weight infants suffering respiratory distress and infants who have suffered from brain hemorrhages. Apart from the most serious cases in each group, doctors are generally unable to determine with any degree of certainty what the ultimate prognosis for these infants will be. Decisions to treat initially, can lead to salvaging infants with very poor developmental prospects and a marginal existence. On the other hand, a decision to withhold initial life-saving treatment may result in the loss of a child who could have had a normal, healthy life.

Whether American courts would uphold or overrule parental refusals to treat in these cases in which it is unclear what the child's best interests are cannot be answered at the present time, since there have been no reported decisions dealing with this type of case. However, certain conclusions can be drawn. The court's decision will depend upon the "precise facts" of each case - the estimated diagnosis and prognosis such as the likely degree of future pain and handicap. If there is conflicting medical opinion, the courts may well leave the final determination to the parents upon assuring themselves that the parents have come to a carefully considered decision which is reasonable under the circumstances. For instance, the Massachusetts Court of Appeal commented that it is clear [270]

> the importance the law attaches to the role of family as next-of-kin in evaluating the appropriateness of treatment in the circumstances of a particular case.

Support for this approach also comes from a recent trilogy of decisions handed down by the New Jersey Supreme Court which permitted the withdrawal of life-sustaining medical treatment. Madam Justice Goribali, who wrote the majority opinion in all three cases, observed: [271]

> Courts are not the proper place to resolve the agonizing personal problems that underlie these cases. Our legal system cannot replace the more intimate struggle that must be borne by the patient, those caring for the patient, and those who care about the patient.

However, in the absence of conflicting medical opinion, the courts will more likely overrule parental refusals to treat where physicians are in favour of continuing medical treatment. In these cases, a balancing of the state's interests in the preservation of life and preserving the ethical integrity of the medical profession may well outweigh parental autonomy.

In addition to balancing the various interests involved, some American courts have sought to rely on the "ordinary/extraordinary" means distinction in attempting to determine whether medical treatment is obligatory (ordinary) or optional (extraordinary) in a particular case.[272]

The problem with the distinction is that while it may provide guidance in extreme cases, it is of little assistance in cases of medical uncertainty, a fact which is illustrated by the remarks made by Hughes, C.J. in Quinlan. He commented:[273]

> [W]hile the record is somewhat hazy in distinguishing between "ordinary" and "extraordinary" measures, one would have to think that the use of the same respirator or like support could be considered "ordinary" in the context of the possibly curable patient but "extraordinary" in the context of the forced sustaining by cardio-respiratory processes of an irreversibly doomed patient.

As Chief Justice Hughes' remarks indicate, the distinction provides no clarification in cases where it is unknown whether the patient is "possibly curable" or "irreversibly doomed."

A potentially useful approach has been proposed by the California Court of Appeal in Barber v. Superior Court of California.[274] In Barber, Compton, J. argued that the use of the terms "ordinary" and "extraordinary" means of treatment "begs the question". Instead he suggested:[275]

> A more rational approach involves the determination of whether the proposed treatment is proportionate or disproportionate in terms of the benefits to be obtained versus the burdens caused.

He explained:[276]

> Under this approach, proportionate treatment is that which, in the view of the patient, has at least a reasonable chance of providing benefits to the patient, which benefits outweigh the burdens attendant to the treatment. Thus, even if a proposed course of treatment might be extremely painful or intrusive, it would still be proportionate treatment if the prognosis was for complete cure or significant improvement in the patient's condition. On the other hand, a treatment which is only minimally painful or intrusive may nonetheless be considered to be disproportionate to the potential

> benefits if the prognosis is virtually hopeless for any significant improvement in condition.

It can be argued that this approach merely states the decisionmaking process which is used in applying the "ordinary/extraordinary" means distinction. An assessment or "guess" still has to be made about the patient's future prognosis. If there is any benefit to this approach, it is that it focuses the decisionmaker's attention on the patient and his or her unique characteristics rather than on the complexity of the technology or treatment to be employed.

4. Procedural Issues

Having established that life-saving medical treatment may be withdrawn from patients in certain cases, American courts have then considered the procedures which should be followed in making and in implementing such decisions. Procedural questions include: (1) Who should make these decisions? (2) Can the decisonmaker make the decision alone or must he consult with others? and (3) If outside consultation is required, can the decisions be made in consultation with a hospital ethics committee or do they require a judicial determination?

Fear of potential civil and/or criminal liability has prompted many American physicians to refuse to comply with parental or family requests to withhold or withdraw life-sustaining treatmeot. Additionally, procedural guidelines have been sought in order to protect helpless and incompetent patients against either premature termination or undue prolongation of life-supporting measures. In response to these concerns, the courts have developed procedures which apply to particular types of cases as well as affording legal immunity to physicians and guardians who comply with these procedural requirments.

Two procedural approaches have been adopted by American courts in order to permit the discontinuation of life-support measures by the parents or guardian of a terminally ill or permanently comatose patient.

(a) The Delegation Approach

The New Jersey Supreme Court in Quinlan faced a situation involving a parental demand to withdraw life-sustaining treatment from a permanently comatose patient over the attending physician's refusals to withdraw treatment.

After examining the issues involved in the case, the court adopted the view that a decision to withdraw treatment from a patient in Karen's condition was a medical decision based upon a determination as to Karen's future prognosis and that medical decisions "should be controlled primarily within the patient-patient-doctor-family relationship". [277] In such cases, the Court rejected the notion of requiring judicial confirmation of these decisions, declaring: [278]

> We consider that a practice of applying to a court to confirm such decisions would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would impossibly cumbersome.

Believing that the physician's refusal to withdraw treatment was primarily motivated by fear of civil or criminal liability, the Court devised an alternative procedure which would provide immunity to physicians and would eliminate the necessity of resorting to the courts in such cases. The procedure involved a two-step consultative process, initially requiring the attending physicians, the guardian and the family to agree that there was no hope that the patient would return to a cognitive, sapient state and that life-saving treatment should be withdrawn. Following this step, a Hospital

"Ethics Committee" or similar body would then be consulted. If the Committee agreed with the prognosis treatment could then be withdrawn with no civil or criminal liability on the part of any of the participants. 279

In Matter of Colyer, 280 the Washington Supreme Court was presented with a petition by a husband to discontinue life support systems from his wife who was in a chronic vegetative state. The Court permitted the life-saving treatment to be withdrawn and discussed the procedural issues involved in decisions to withhold treatment in such cases.

A distinction was drawn between Quinlan and Saikewicz types of cases. Cases which are similar to Quinlan did not require judicial intervention but the Court was careful to point out: 281

> We in no way abdicate, however, the authority of the courts to hear and decide any case brought before it.

The Washington Supreme Court rejected the use of a multidisciplinary "ethics committee" which had been recommended in Quinlan, noting that such committees had been criticized for being "amorphous, for ... use of non-medical personnel to reach a medical decision, and for ... bureacratic intermeddling." [282]

Instead, the Court recommended that a "prognosis board" should be used, consisting of at least two physicians who were qualified with respect to assessing the patient's condition, as well as the attending physician. These physicians had to unanimously agree that there was no reasonable possibility that the patient would return to a sapient state. If the physicians failed to agree then the courts would intervene.

In Saikewicz type cases, where the patient has always been incompetent and family members disagree, or if there is no family member to serve as a guardian, the Court held that courts "may be required to intervene". [283]

(b) The Non-Delegation Approach

An alternative approach was adopted by the Supreme Judicial Court of Massachusetts in Saikewicz. [284] It rejected the approach taken by the Quinlan court, viewing it as an "attempt to shift the ultimate decisionmaking responsibility away from the duly established courts of proper jurisdiction" to an ethics committee. These committees or like bodies could play a useful role, but in an advisory capacity only, and the Court stressed that consultation with such committees was optional and not a required procedure.

The Massachusetts Court also disagreed with the view expressed by the Quinlan court that the withdrawal of life-sustaining treatment from a person who was unable to decide for himself was primarily a medical decision to be decided by doctors. Liacos, J. explained that [285]

> such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the 'morality and conscience of our society', no matter how highly motivated or impressively constituted.

Following the Saikewicz decision uncertainty prevailed within the Massachusetts medical community as to whether life-prolonging or life-sustaining treatment could ever be discontinued from terminally ill, incompetent patients in the absence of a prior court order. Some physicians interpreted Saikewicz to mean that judicial approval was required to withdraw treatment from an incompetent patient, even in cases of brain death. [286]

In light of this uncertainty, the Massachusetts Appeals Court attempted to clarify the Supreme Judicial Court's opinion in Matter of Dinnerstein. [287] The issue presented to the Court in Dinnerstein was whether a physician could lawfully direct that resuscitation measures be withheld from an incompetent, terminally ill patient, in a vegetative state, in the event of cardiac or respiratory arrest without obtaining a prior court order.

The Massachusetts Appeals Court held that in this type of case it was unnecessary for the physician to obtain prior court approval to withdraw treatment. Such cases were distinguishable from the Saikewicz case which had involved a situation of choice. Chemotherapy, though it could not permanently cure Joseph Saikewicz's leukemia, nevertheless could make possible a temporary remission which would allow him an "extension of normal, functioning existence for a period of months or years." [288]

That was impossible in this case, or in any other case where the patient was in the final stages of an "unremitting, incurable mortal illness." In these cases, treatment could neither cure nor could it relieve the patient's illness. Therefore, there was no "significant treatment choice or election" which could have been made by a patient, if competent, as was the case in Saikewicz. Such cases in the Court's view [289]

> present[s] a question peculiarly within the competence of the medical profession of what measures are appropriate to ease the imminent passing of an irreversibly, terminally ill patient in light of the patient's history and condition and the wishes of her family. That question is not one for judicial decision, but one for the attending physician, ... and subject to court review only to the extent that it may be contended that he has failed to exercise 'the degree and skill of the average qualified practitioner ...

Subsequently, in Matter of Spring the Supreme Judicial Court approved the result in Dinnerstein "without approving of all that [was] said in the opinion of the Appeals Court." [290]

Although the Supreme Judicial Court reiterated its disapproval of the shifting of the ultimate decision-making authority away from the courts, it refused to establish a "requirement of prior judicial approval that would otherwise not exist." [291] The Court expressly rejected the Appeal Court's holding in Dinnerstein which had implied that prior judicial approval for the withdrawal of medical treatment from incompetent patients was necessary in all cases, except where the patient was in the terminal stages of an incurable illness or in a persistent vegetative state.

The Supreme Judicial Court made it clear that there are a variety of circumstances which should be considered in deciding whether prior judicial approval should be sought. However, the Court was not called upon, nor did it consider it necessary on the facts of the case before it to determine what combination of factors and circumstances would mandate or make prior judicial approval desirable. [292]

Braucher, J. concluded that if medical decisions are made privately to withdraw treatment from incompetent patients, they must be made responsibly and are subject to judicial review. Liability will follow for actions which are taken in bad faith or are grievously unreasonable, although evidence that an ethics committee was consulted and concurred with the decision "may be highly persuasive on issues of good faith and good medical practice." [293]

However, the Court stressed that if the Court is called upon to decide the legal question "whether treatment may be withheld, it must decide that question and not delegate it to some private person or group."[294] Furthermore, a physician who obtained prior court approval to withdraw life-saving treatment is immune from criminal and civil liability unless he or she negligently carried out the court's order.

The New York Supreme Court Appellate Divison in Eichner v. Dillon,[295] considered the issue of whether judicial approval was necessary in order to discontinue life-sustaining treatment from a terminally ill and comatose patient.

In holding that judicial intervention was required before any treatment could be withdrawn, Mr. Justice Mollen reasoned "that the societal interests are so great that the courts have no choice but to intervene and examine each case on an individual basis."[296] He then set out a mandatory procedure to be followed whenever it was proposed that treatment should be withdrawn from a patient:[297]

> (1) The attending physicians must certify that the patient is terminally ill and in a chronic, vegetative state;
>
> (2) The prognosis must be confirmed by a majority of the hospital ethics committee (if none exists, a committee shall be appointed);

(3) A proceeding shall be commenced for an appointment as Committee of the incompetent, and for permission to withdraw life-sustaining treatment;

(4) The Attorney General and District Attorney should be given notice of the proceeding; and

(5) A guardian ad litem should be appointed to protect the patient.

Once these procedures had been complied with and if the court agreed that treatment should be withdrawn, then no criminal or civil liability will attach to any of the participants for withdrawing life-sustaining treatment.

On appeal, the New York Court of Appeals found that it was not "inappropriate for those charged with the care of incompetent persons to apply to the courts for a ruling on the propriety of conduct which might seriously affect their charges." However, the Appeals Court emphasized "that any such procedure is optional." 298

Similar conclusions have been reached in other American jurisdictions. In Barber v. Superior Court of California, the California Court of Appeal held "in the absence of legislative guidance, ... no legal requirement that prior judicial approval is necessary before any decision to withdraw treatment can be made" and further that requiring judicial intervention in all cases "may be unwise." 299

The Louisiana Supreme Court in Re P.V.W., held that an appropriate representative may assert a permanently comatose child's right to have treatment withdrawn, "either after the event in civil or criminal proceedings or before the event in a declaratory judgment action." 300

American courts appear to be moving towards a consensus that judicial involvement is not generally required in cases involving the withdrawal of treatment from permanently comatose patients. They will intervene in cases where there is a disagreement as to the proper course of action among the parties involved and if they are asked to render an opinion in such cases, they will do so.

Any physician, guardian or other participant who withdraws treatment with the court's approval is immune from civil or criminal liability as long as their actions are performed in good faith and executed with due care.

The courts have also recognized that hospital ethics committees can play a valuable role in dealing with these difficult issues though there is disagreement as to the precise role these committees should play. However, there is a growing consensus that when treatment has been withdrawn in the absence of court approval, a committee's concurrence with the decision will be persuasive with regard to issues of good medical practice and good faith if subsequent litigation does ensue.

C. Anglo-Canadian Jurisprudence

1. The British Position

Few cases concerning the withdrawal of life-sustaining medical treatment have come before the English Courts. The leading reported English case In Re B,[301] involved a Down's Syndrome infant who suffered from an intestinal blockage. Without surgery the infant would starve to death within a few days. With the surgery there was a possibility that she would die within a few months, although it was probable that her life expectancy would be 20 to 30 years. Her parents refused to consent to the operation believing that it was in her best interests to be allowed to die rather than face a life of severe physical and mental handicaps.

In ordering that the treatment be given, Lord Justice Templeman observed that "while great weight ought to be given to the views of the parents they are not the views which necessarily must prevail".[302] He indicated that the court's primary duty and "paramount consideration" is to decide what is in the best interests of the child and in reaching this decision, the court must determine:[303]

> ... whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die.

He continued, stating:

> There may be cases, I know not, of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion ...

However, in this case the evidence before the court showed that if the operation was permitted and was successful, although the child would suffer from the deficiencies associated with mongolism, she would enjoy the normal life of a mongoloid person. Therefore, it was not the prerogative of the court to say that such a life should be extinguished.

The other relevant case, R. v. Arthur,[304] involved the criminal prosecution of a pediatrician for the death of a Down's Syndrome infant. The infant was rejected by his parents at birth and Dr. Arthur wrote a note on the infant's chart: 'Parents do not wish it to survive. Nursing care only.' He prescribed a sedative drug (DF 118) to be given to alleviate the infant's distress. The infant died 69 hours after its birth and an anonymous tip, alleging that the baby had been drugged and starved to death was made. Dr. Arthur was charged with murder. During the course of the trial medical experts testified that Dr. Arthur's actions fell "within the current accepted norms of medical practice."[305] The case collapsed because of irregularities in the medical evidence presented by the prosecution and due to the fact that the prosecution failed to prove that the infant had starved to death, since its weight at death was the same as it was at birth.

English legal commentators have suggested that "the decision establishes little in the way of principle, and to a large extent turns on its own narrow facts."[306] Nevertheless, the comments of Farquharson, J. in his charge to the jury are significant. In his summation, he indicated that it was lawful to sedate an infant and to discontinue further care including food, other drugs or surgery providing two conditions are met: (1) the child is 'irreversibly disabled', and (2) rejected by its parents.[307]

It appears difficult to reconcile the two decisions. In Re B states that parental wishes are secondary to the best interests of the child, while Arthur seems to suggest that parental autonomy should be respected in a decision to withhold treatment from a severely handicapped child. In fact, the decisions may not be irreconcilable. The infant in Re B had, apart from her intestinal obstruction, no other complications while the pathology report in Arthur revealed that the infant had (in addition to the Down's Syndrome) "calcification of the brain, fibroelastosis of the heart and congenital abnormalities of the lung".[308] In addition, evidence presented to the court in Arthur was that normally a mother does not produce milk for three days after birth and a normal child does not suffer if he is given only water, until the mother's milk becomes available. The infant in Arthur died within three days apparently as a result of his congenital abnormalities and not as a result of starvation.

Thus, the two cases are distinguishable. Medical treatment could restore B to the life of a normal, healthy mongoloid while the infant in Arthur was likely terminally ill at birth and would have died with or without treatment.

On this view, it is submitted that the English Courts are in agreement with their American counterparts. Each recognizes that parental decisions are to be respected but that parents do not have absolute discretion regarding the treatment or nontreatment of their children.

In both countries, the courts' primary concern is to protect the best interests of the child. The fact that a child may be physically or mentally handicapped does not mean that continued life is not in the child's best interests. However, parental decisions to withdraw life-saving medical treatment will be upheld where the child is terminally ill and/or will face a life of intolerable suffering, but parents cannot otherwise withhold medical treatment which is necessary to save the child's life. Parental autonomy will also be given greater weight when the benefit is unclear or is possible only at great risk or suffering.

2. Canadian Law

(a) Criminal Code Provisions

Section 215 of the Criminal Code imposes a duty upon parents and guardians to provide "necessaries of life" to their children under the age of sixteen.[309] A duty is also imposed upon all persons to provide "necessaries of life" to any person "under his charge" who is unable to withdraw from his charge by reason of detention, age, illness, insanity or other cause and who is unable to provide himself with the necessaries of life. [310]

"Necessaries of life" has been defined to include anything necessary for the preservation of life and includes medical care and treatment.[311]

Although food and water are considered the basic necessities of life, in recent years there has been a growing medical, ethical and legal controversy over the permissibility of withholding artificial nutrition and hydration (AN & H) from dying and permanently comatose patients.[312] This issue has arisen because many medical professionals believe that terminal patients die more comfortably if they are not given artificial nutrition and hydration.

In the United States, the Council on Ethical and Judicial Affairs of the American Medical Association Council issued a policy statement in 1986, on "Withholding or Withdrawing Life-Prolonging Treatment," in which it stated that "life-prolonging medical treatment included medication and artificial or technologically supplied respiration, nutrition and hydration," and held that such treatments "are all subject to balancing benefits and burdens for either terminally ill or incompetent patients".[313] This view was adopted in an earlier judicial decision, Barber v. Superior Court of The State of California,[314] in which the California Court of Appeal held that the withdrawal of intravenous tubes providing hydration and nourishment from a permanently comatose patient by two medical doctors, was not an unlawful failure to perform a legal duty. Compton, J. speaking for the Court, reasoned:[315]

> ... we view the use of an intravenous administration of nourishment and fluid under the circumstances, as being the same as the use of a respirator or other form of life support equipment.

> The prosecution would have us draw a distinction between the use of mechanical feeding devices such as respirators and intravenous tubes. The distinction urged seems to be based more on the emotional symbolism of providing food and water to those incapable of providing for themselves rather than on any rational difference in cases such as the one at bench ...
>
> Medical nutrition and hydration may not always provide net benefits to patients. Medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration. Their benefits and burdens ought to be evaluated in the same manner as any other medical procedure.

In Canada, Dr. John Watts, chairman of the Canadian Pediatric Society's bioethics committee has stated:[316]

> Babies doomed to die get food and water and warmth, but no medical care ... However, a dying infant should not be fed through intravenous tubes if he can't eat normally ... Technically speaking it's being starved. [But doctors withhold I.V. feeding because] of the distress imposed for no long-term benefit.

As for other medical treatments, i.e., surgery or antibiotics, again it is difficult to be precise. Magnet maintains that it is permissible to withhold minor surgery in appropriate cases, but he sees the withholding of antibiotic drugs to combat infection as problematic since they "would tend to make a patient more comfortable".[317] Other commentators have suggested the duty to provide necessaries of life under s.215 applies only to the provision of "ordinary" care. Bernard Dickens argues:[318]

> Accordingly, it may appear that when a child has no potential for cognitive, sapient existence but will persist in only a vegetative state, and when a child has sufficient neurological function to be conscious of pain and suffering and has the likelihood of experiencing little more in life than such chronic affliction, the employment of what are variously described as artificial, mechanical, invasive, aggressive or herioc means necessary to sustain life may be extraordinary care, which there is no legal duty to undertake or afford. Comfort or palliative measures such as warmth, sanitary care and in most cases nutrition will set the limits of the ordinary treatment which there is a duty to provide, occupying the services more of nursing than of medicine.

With respect to the provision of antibiotics, he writes:[319]

> Similarly, while antibiotics may normally be ordinary treatment, they may be extraordinary where their use, for instance to relieve pneumonia, will merely set the scene for an agonizing or vegetative death from another cause shortly thereafter.

Notwithstanding these commentators' views, the Criminal Code specifically provides that everyone who has a duty to supply necessaries to another commits an offence, if they fail without 'lawful excuse' to perform that duty if it endangers the life or permanently injures the health of the person to whom the duty is owed.[320]

For parents an inability to provide a child with necessaries has constituted a lawful excuse,[321] but, parents cannot refuse life-saving medical treatment on the basis of their religious beliefs.[322]

It is less clear whether doctors, hospitals and nurses are included within s.215 since there is disagreement about whether a hospitalized infant is "under the charge" of the attending doctor, hospital or the nurses. Magnet submits that the parents are the legal guardians of the child and until their guardianship is interfered with the child is not "under the charge" of other parties.[323] However, the Law Reform Commission has taken a contrary position, stating:[324]

> The expression "under his charge" includes the care and custody of someone who is helpless whether or not such care and custody is imposed by law or voluntarily' incurred. Someone may be under another's charge because of a

> contract or relationship. Hospitals, doctors, nurses and others who contract to care for someone who is helpless because of illness, insanity or age thus have a duty to supply necessaries.

It is submitted that the Commission's view is a more accurate reflection of the position of the medical caregivers and the hospital. For the physician, reliance on a parental demand to withdraw life-sustaining medical treatment would not be sufficient to constitute a "lawful excuse" if such treatment were medically indicated.

In addition, Section 217 of the Criminal Code further provides:

> Every one who undertakes to do an act is under a legal duty to do it if an omission to do an act is or may be dangerous to life.

A literal reading of Section 217 would require physicians, once they have initiated treatment, to continue such treatment though it may be no longer useful and serve only to prolong the patient's suffering and inevitable death. This provision has been part of the Criminal Code since its inception and thus predates the advent of modern medical technology with its extraordinary means of prolonging human life.

The law in practice in this area does not reflect the law as it appears in the books. Doctors across Canada, in consultation with patients and their families (where applicable) withdraw life-support measures which permit the patient to die in terminal cases. This practice is consistent with good medical ethics and good medical practice and doctors have not been prosecuted for the cessation of treatment in such cases.

The Law Reform Commission has accordingly suggested that a specific provision be inserted in the Criminal Code that, "contrary to the general rule regarding crimes by omission, no one has a duty to continue medical treatment that is therapeutically useless or contrary to the wishes of the patient." 325

Thus, a physician who determines that medical treatment would be futile or that treatment would merely prolong an infant's dying would be unlikely to face criminal prosecution. However, Section 217 must be read in conjunction with other Criminal Code provisions particularly the sections dealing with criminal negligence.

Where a doctor fails to continue treatment he is theoretically in breach of the duties imposed on him by Sections 215 and 217 of the Criminal Code. In the event that his actions or inaction result in the child's death, he (as well as the parents) could be charged with criminal negligence and/or homicide.

Section 229 provides:

> Culpable homicide is murder
>
> (a) where the person who causes the death of a human being
>
> (i) means to cause his death.

Omissions are covered by Section 224:

> Where a person, by an act or an omission, does anything that results in the death of a human being, he causes the death of that human being notwithstanding that death from that cause might have been prevented by resorting to proper means.

Theoretically prosecution is possible in a passive euthanasia case for several reasons. First, the definition of causing death is extremely broad in criminal law. Causation may be either causation in fact or, causation in law. In the leading case, Smithers v. The Queen [326] the Supreme Court held that doing anything beyond the de minimis range which contributes to or accelerates death is all that the Crown is required to prove to sustain a charge of homicide.

In R. v. Kitching and Adams,[327] the defendants threw the deceased to the ground resulting in a skull fracture and brain damage. Subsequently, doctors removed the deceased's kidneys and disconnected him from life support systems. The defence argued that the cause of death was the removal of the organs. At trial, the Court rejected this contention on the basis that the actions of the physicians were irrelevant to the guilt of the accused since the evidence showed the deceased could not have lasted more than a short period of time even with artificial assistance. Sullivan, J.A. noted[328]

> that the conduct of a defendant in a criminal trial need not be shown to be the sole or 'the effective' cause of a crime. It is sufficient if it is a cause. ... the authorities are clear that there may be two or more independent operative causes of death.

The doctors were not charged in this case but they could well have been since there was clear evidence that the deceased was alive (brain death had not occurred) at the time his kidneys were removed. Subsequently, in R. v. Torbiak and Gillis,[329] the Ontario Court of Appeal held that there was no doubt that the cause of death in law was a gunshot wound inflicted by the accused though the cause of death in fact was the conservative couse of non-interventional treatment chosen by the treating physicians.

These cases illustrate two propositions. One is that a course of nontreatment can amount to causing death under criminal law and, second, the absence of cases indicates that there is an implicit policy of non-prosecution. Nevertheless, given appropriate circumstances and a willing prosecutor, the susceptability remains.

For criminal law purposes, compassionate motives are irrelevant. The law is concerned solely with intention. Did the doctor intend the infant's death? [330] For general intent offences, i.e., manslaughter and criminal negligence, recklessness as to whether or not the defined harm should occur is sufficient to sustain either charge. For specific intent offences, i.e., murder (s.229(a)(b)), something more is required. [331] The degree of foresight can support an inference that a person intended death. [332] Another inference is that a person intends the natural and probable consequences of their actions. Thus, a physician who foresees (if not intends) that death is certain or substantially certain will likely be held to have intended that consequence. [333] In most instances in the neonatal context the physician' "intention" or "foresight" would be death and therefore a murder charge would be highly probable.

Alternatively, where the requisite intent (mens rea) is not present to sustain a charge of murder, a physician could be charged with criminal negligence.[334] Criminal negligence offences are categorized on the basis of severity, depending on whether bodily harm[335] or death ensues.[336]

The concept of negligence in the civil law is the objective standard of the reasonable man - a departure from that standard forms the basis of civil liability. Criminal negligence differs from that in civil cases in that both the actus reas and mens rea must be proven. However the caselaw reflects different approaches to the required mens rea.

One approach is that suggested in R. v. Tutton and Tutton[337] which distinguished between acts of commission and acts of omission. In a case based on acts of omission, the test is a subjective one requiring that the accused in failing to administer medical assistance knew that there was a risk to the life or safety of that child and unjustifiably took that risk, or closed his or her mind to any such risk out of a disregard for the child's life or safety. It was not simply a matter of determining what reasonable parents (or physicians) might have done (an objective test) as would be the case for acts of commission.

Another approach is taken by the Alberta Court of Appeal. The Court acknowledges that the test is advertant negligence coupled with the presence of some aggravating feature such as "a recklessness of the consequences or an indifference to the lives or safety of others." [338]

A third approach is to ignore the theory of mens rea and apply a purely objective approach. In R. v. Rogers, a medical case in which unorthodox treatments were used, the Court stated that the standard required was an objective one which is tested objectively by the standards of reasonable people. [339] A similar test was applied in R. v. Waite, [340] a case involving driving. In that case, the Court held that the requisite intent could be inferred from the driving or act of commission and if the driving or other act constituted a marked departure from the conduct that could be expected of a reasonable man in the same circumstances, then in the absence of some explanation, the act itself may determine culpability. The Crown is not required to prove a subjective element of deliberate assumption of the risk in order to obtain a conviction.

Since there have been few prosecutions of medical personnel, it is not clear which test would be applicable. If the objective approach is adopted arguably current medical practice would provide a "defence" in the sense that there is not a marked departure from the standard. Yet the problem arises that the standard itself (if it permits nontreatment with the knowledge that it will cause death) may be unlawful.

All of these elements of criminal law relate to the issue of consent - can the parents "consent" to nontreatment when they, and the doctor, foresee or intend the consequence of death. The following factors suggest they cannot:

1. Both the parents and doctor are under a duty pursuant to s.215.
2. A person cannot consent to death or grievous bodily harm. S.14 of the Code as well as the common law. (Carriere, supra).
3. If a person cannot consent to death for themselves, it is doubtful that they can provide a surrogate consent for the death of another.
4. Finally, with respect to children, it is arguable that consent is irrelevant since the Code has historically regulated conduct with respect to children from the time of conception onward. First,

> as a fetus with the abortion laws. In the latest Morgentaler decision, Wilson, J. suggests that the right of the parent to control her own body may have to be balanced against the right of a viable fetus. Second, the child at birth is protected, s.238 [341] makes consent irrelevant, and third after birth, the child is a human being and one cannot consent to its death. s.223. [342]

It is essential to recognize that all of these provisions have been developed without regard to the medical situation. Although the theoretical possibility of prosecution may seem unfair, it is submitted that specific exemptions should not be created to absolve medical personnel from criminal responsibility where their actions are outrageous or depart significantly from societal and medical norms. Nevertheless there are, as will be posited in Chapters 3 and 4, circumstances in which active treatment could be withdrawn. Given the theoretical possibility of prosecution, it is submitted that a provision should be added to the Criminal Code which would provide a defence to physicians who withdraw active treatment for seriously ill or defective infants in these rare cases.

(b) Child Welfare Legislation

As discussed earlier under Consent to Treatment, Alberta's Child Welfare Act imposes a duty on everyone to report to child welfare authorities that a child is in need of protective services, when a child's life is endangered because of the guardian's failure to provide the child with essential medical or surgical care.[343]

(c) Caselaw

To date there is little Canadian caselaw involving the withholding of life-saving medical treatment from infants or children.

The Dawson Case

The Dawson case marked the first reported Canadian case to confront the issue of the scope of parental autonomy with respect to decisions regarding the withdrawing of medical treatment from a severely handicapped child.[344]

Stephen Dawson was a seven year old profoundly mentally and physically handicapped child who suffered from a malfunctioning brain shunt which had been implanted in order to drain off excess cerebro-spinal fluid from his brain. His parents initially consented to surgery to replace the shunt but later withdrew their consent believing that it was in his best interests to be allowed to die with dignity rather than endure a life of suffering. The Superintendent of Child Services of British Columbia apprehended Stephen on the basis that he was a child "in need of protection" because he was being deprived of "necessary medical attention" and applied to the court for an interim custody order to authorize the operation.[345]

In Provincial Court, Judge Patricia Byrne refused to grant the application and ordered that Stephen be returned to his parents' custody. This decision was set aside by Mr. Justice Mackenzie of the British Columbia Supreme Court, He awarded custody to the Superintendent and ordered the surgery. Although the decisions concern the same child, different medical evidence was presented to each court so that the reasoning of both courts must be considered in light of the different facts before them. 346

Medical evidence was presented to Judge Byrne that Stephen was,[347]

> ... in a vegetative state, ... has no reflex movement, except is responsive and sensitive to pain. He has a stereotyped response to pain ... has unorganized random movements of his head, eyes and limbs. He has no cognitive awareness of his surroundings ... He has lost response to touch ... [and] is not capable of progress in the cognitive sense.

Judge Byrne also observed: "All doctors agree that if the shunt is not replaced Stephen will die in the near future ...".[348]

She distinguished the facts in this case from those in Re B,[349] since the English court had ordered treatment on the basis that it was too early to tell the extent of the infant's physical and mental defects, while in Stephen's case, his hopeless prognosis was known.

In reaching her decision, Judge Byrne adopted the principles enunciated in Quinlan, namely, that an incompetent patient has the right to refuse life-sustaining medical treatment and that this right may be exercised on behalf of the incompetent by the family in consultation with their physicians.

She then distinguished treatments "where continued treatment serves only to prolong a life inflicted with an incurable condition",[350] from those that can cure or alleviate the patient's condition, and characterized the shunt revision in the former category.

Continuing the Quinlan analysis, she concluded that, "in the circumstances of this case, the shunt is a life-support system" [analogous to a respirator] and that the shunt revision constituted extraordinary treatment. 351 In her view, Stephen was not a child "in need of protection" who was being "deprived of necessary medical attention" under the relevant provisions of the Family And Child Services Act since "necessary medical attention" referred to ordinary and not extraordinary treatment.

Judge Byrne further held that the shunt revision would constitute cruel and unusual treatment of Stephen thereby violating his right not to be subjected to such treatment pursuant to s.12 of the Canadian Charter of Rights and Freedoms. 352

Being satisfied that Stephen was "a well-cared for and loved child", she ordered that he be returned to the custody of his parents pursuant to the Family and Child Services Act.

On appeal to the British Columbia Supreme Court, Mackenzie, J. invoked the parens patriae jurisdiction of the court to hold a new trial.[353]

Additional medical evidence was presented to the Supreme Court by other pediatric specialists that, without the surgery, Stephen might not die but would continue to live with additional brain damage, decreased abilities, and increased pain.

Mr. Justice Mackenzie carefully considered the views of the parents in making his decision but he found the evidence of the doctors and other professionals who had worked closely with Stephen more credible than the views of the parents who had hardly seen him since he had been institutionalized. The evidence, in his opinion, showed that the parents believed that Stephen would be better off dead long before the shunt revision was in issue, and he rejected their contention that they would give their consent to the surgery if they thought it would free Stephen from pain, since he noted that they refused to accept competent medical evidence that this would be the case.

Although parents' wishes are to be carefully weighed and considered, Mackenzie, J. emphasized that the court's "central concern" in exercising its parens patriae jurisdiction is to determine what is in the child's best interests.

He stated the issue before the court was: [354]

> ... not a "right to die" situation where the courts are concerned with people who are terminally ill from incurable conditions. Rather it is a question of whether S. has the right to receive appropriate medical and surgical care of a relatively simple kind which will assure to him the continuation of his life such as it is.

In holding that the surgery should be performed, Mackenzie, J. cited the principles on which his decision was based: [355]

> I am satisfied that the laws of our society are structured to preserve, protect and maintain human life and that in the exercise of its inherent jurisdiction this court could not sanction the termination of a life except for the most coercive reasons. The presumption must be in favor of life.
>
> I do not think that it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that

6

> person's life to be so low as not to be deserving of continuance.

He continued: 356

> Neither could this court sanction the willful withholding of surgical therapy where such withholding could result not necessarily in death but in a prolongation of life for an indeterminant time but in a more impoverished and more agonizing form.

This judgment affirms the strong, though not absolute, sanctity of life principle espoused by the English Court of Appeal in Re B. Parents do not have the discretion to refuse life-saving medical treatment from a severely handicapped child any more than they are able to refuse such treatment from a normal child unless it is proven that "the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion." 357

Stephen's prognosis was uncertain and therefore did not meet this stringent test, rather his life was "still so imponderable that it would be wrong to let [him] die". 358

It has been suggested by some legal commentators that the decision of each court was consistent with the facts before it and that the differing principles expressed should guide decisionmakers in dealing with both types of cases.[359]

An example of a case which illustrates the circumstances in which a Court would be driven to a different conclusion is Coutre-Jacquet v. Montreal Children's Hospital.[360] In that case, the hospital providing treatment petitioned the court for a judicial authorization for chemotherapy treatment for a three year old girl suffering from a rare form of cancer. The child's mother had peviously consented to chemotherapy treatments but refused to consent to further treatment because of the adverse side effects of the treatment and the limited possibility that such treatment could offer for a cure. The trial judge granted the hospital's petition but the decision was unanimously overturned by the Quebec Court of Appeal.

The Court stated that it was not the Court's role to substitute itself for the person having parental authority and to decide in his or her place. Rather, the Court's role is to correct a decision which is very clearly wrong. This was not the case here. First, the mother was fully informed about the nature of the child's illness - both about her chances for survival without further treatment as well as the nature and risks of continued treatment. Second, the adverse effects of the treatment were extreme; involving almost total deterioration of kidney function, hearing loss and liver dysfunction. In addition, the child suffered from "major emotional problems" as a result of her illness. These effects would be exacerbated by further treatment and at best the treatment could only offer a 10 - 20% chance of a cure. The Court also noted that the child's mother and grandmother had witnessed the discomfort and suffering the child had endured through three previous series of treatments.

After considering all of the circumstances in which the mother had made her decision, the Court held that the mother's decision to refuse further treatment was in the child's best interest and would therefore not be tampered with.

Another case in which a court upheld a parental decision to refuse further treatment was Re L.D.K. [351] The case involved a 12 year old Jehovah's Witness suffering from leukemia. Both the child and her parents objected to the chemotherapy treatment proposed by the hospital since it would necessitate blood transfusions. L. herself, testified that she would fight with all of her strength against the blood transfusion therapy. She further testified that she rejected the treatment, not only because of her religious beliefs but because she did not want to experience the pain and suffering from the terrible side-effects (i.e., nausea, vomiting, loss of hair, sterility, death from heart failure, among others) which she had observed in other children undergoing chemotherapy. Medical evidence was also presented to the Court which showed that even with the chemotherapy the chance of a cure was probably no more than 30% at best.

L. and her parents had sought additional medical advice and proposed an alternative treatment plan involving mega-vitamin therapy. Throughout this treatment she would not be hospitalized but would remain with relatives and her family.

The Court refused to override the parents' and child's wishes by ordering chemotherapy treatments. The trial judge concluded: [362]

> From what I have heard this child's life is equally in danger whichever path is taken, whether she is left here and subjected to this treatment or she

> is allowed to leave and be treated according to the wishes and beliefs of herself and her parents.

Since the chemotherapy treatment addressed the child's disease only in a physical sense, without considering the child's emotional or religious beliefs, the Court held that the balance tipped in favour of the mega-vitamin treatments proposed by L. and her parents.

Thus Canadian law is consistent with the reasoning of American and British courts that poor quality of life alone is not a legal justification for withholding life-saving medical treatment. [363] Similarly, Canadian law does not mandate an absolute sanctity of life ethic. Parents' refusal of further life-saving treatment will be upheld by the courts - where it is certain that a child's life is bound to be full of pain and suffering and parents and physicians may withdraw further lifesaving treatment from children who are comatose or in a persistent vegetative state. Also, parental decisions to refuse a particular form of treatment will be respected where the parent chooses an alternative medically recognized course of treatment. Again, this approach is consistent with the views expressed by British and American courts. [364]

(d) Constitutional Law

The entrenchment of the Canadian Charter of Rights and Freedoms has given Canadians a number of constitutionally protected rights which are relevant in decisions to withhold or withdraw lifesaving treatment from defective infants.

The relevant provisions include the following: [365]

> Section 2: Everyone has the following fundamental freedoms:
>
> (a) Freedom of conscience and religion
>
> Section 7: Everyone has the right to life, liberty and security of person and the right not to be deprived thereof except in accordance with the principles of fundamental justice
>
> Section 12: Everyone has the right not to be subjected to cruel and unusual punishment.

Since the Charter has only recently been enacted the full scope and extent of these rights have yet to be determined. However, the few cases that have thus far come before the courts regarding the withdrawal of lifesaving treatment from children shed some light on the meaning and application of these provisions.

Re D,[366] involved a seriously ill infant who required blood transfusions which his parents refused on religious grounds. They argued that certain sections of Alberta's Child Welfare Act which permitted medical treatment to be given contrary to the parents' wishes were unconstitutional since they offended s.2(a) of the Charter guaranteeing freedom of conscience and religion. Judge Catonio disagreed, stating:[367]

> In my view, the legislation being inpugned is not legislation in relation to religion but rather in relation to child welfare and public health. It is true that certain sections of the Child Welfare Act may affect Jehovah's Witnesses in the exercise of their religious beliefs but the pith and substance of the legislation is not religion and therefore does not contravene the guarantee of freedom of religion as enshrined in the Canadian Constitution Act, 1982.

In R. v. Tutton and Tutton, 368 the Ontario Court of Appeal held that it was not a "lawful excuse" for parents who, knowing that their child's life was in danger, refused to supply the necessary treatment because it was contrary to their religious beliefs and the Court further concluded that, "[t]he guarantee of freedom of conscience and religion as enshrined in the Charter has nothing to do with this issue."[369]

In M. (R.E.D.) v. Director of Child Welfare,[370] an extremely premature infant weighing only 400 grams (less than a pound) was born in Calgary and was immediately transferred to the neonatal intensive care unit at the Foothills Hospital. The parents refused to consent to blood transfusions for the infant that were deemed essential by the neonatal intensive care team. As a result, the child was apprehended under the provisions of the Child Welfare Act and three separate orders were granted by two provincial court judges permitting blood transfusions. On appeal, it was argued that provisions 20 and 29 of the Child Welfare Act which abrogate the right of parents to determine the medical treatment of their child was invalid because of the application of the Charter.

Virtue, J. considered the law both before and after the Charter, and stated:[371]

> The courts have long held the view that they are the protector of children and that in matters involving children the welfare of the child is the paramount consideration. I do not consider that the framers of the Charter intended to upset the special role of the Court nor the principle that the best interest of the child should prevail.

He then considered the effect of various rights under the Charter in the case before him.

First, he examined the provisions of the Child Welfare Act in relation to s.7 of the Charter. The Act, he concluded, did not deprive the child of the right to life under s.7 but protected that right. Even if one accepted the view that the parents had a corresponding s.7 right to liberty and thus a right to be free from state interference, when balanced against the child's right to life, the latter right took precedence.

Virtue, J. then considered the argument that the provisions of the Act constituted an infringement of the parent's freedom of conscience under s.2 of the Charter. He noted that the effect of the Act (though not its purpose) did infringe upon the parents' right to direct the medical treatment of their child in accordance with their religious beliefs. However, he concluded that religious freedom may be subject to qualification where necessary to protect the rights of others, stating:[372]

> It would overshoot the actual purpose of the Charter if religious freedom were allowed to be exercised in such a way as to deprive a baby of a realistic chance to life.

There was no violation of the parents' right to be free from unreasonable search and seizure under s.8 of the Charter, since the parents did not have the right to possess the infant as if she were a chattel, nor were the infant's rights under s.8 violated, since the actions taken under the Child Welfare Act were not unreasonable and were for her benefit and protection.

The Act did not violate s.12 of the Charter which enshrines the right not to be subject to cruel and unusual punishment, since Virtue, J. reasoned that this section was not intended to cover medical treatment but was "restricted to penal or quasi-penal matters." 373

Finally, the Court held that neither the infant's nor her parents' right to equality under s.15 of the Charter was violated. Section 15 of the Charter states:

> (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.
>
> (2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because or race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

As the infant did not have any religious beliefs, her rights under this section of the Charter were not infringed.[374] Since the Act applied equally to all parents who withhold their consent to essential medical treatment, the parents were not discriminated against although the Court recognized that the Act may have a greater impact in some cases on the religious conscience of parents who are Jehovah's Witnesses. Nevertheless, in applying the test of a "fair minded person", weighing the purpose of the legislation against its effects on persons who may be adversely affected, Virtue, J. concluded that, such a person would consider the legislative provisions under the Child Welfare Act which allow a child to receive essential medical treatment against the wishes of the parents who refuse for religious reasons to be reasonable and fair.

In any event, even if the legislation were found to be discriminatory, he held that it could be justified under s.1 of the Charter as coming within "such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society."[375]

A similar determination was reached by Russell, P.C.J. of the Alberta Provincial Court in Re R.K.[376] In weighing and balancing the competing interests of the infant and the parents, she concluded that neither the parents' freedom of religion guaranteed by s.2(a) of the Charter nor their liberty right to make decisions for their child pursuant to s.7 of the Charter could outweigh the child's right "to life or quality of life".

In Re Goyette,[377] the parents refused to consent to a lifesaving operation for their 26 month old infant who suffered from Down's Syndrome, on the basis of the child's poor quality of life. The Quebec Children's Aid Society applied for authorization to permit the surgery. In granting the application the Quebec Superior Court found the infant was a "human being" having a legal personality and legal rights. One of these rights was the right to life and to assistance when that life was in peril, guaranteed by s.7 of the Charter. The Court held that this right takes precedence over any inconvenience that may be caused to the handicapped person, the parents, or to society.

Thus far, the Supreme Court of Canada has not been asked to render a decision on this issue. However, the recent decision of the Court in the Morgentaler[378] case may shed some light on the approach the Court might adopt in considering an application by a parent or other surrogate decisionmaker to withdraw lifesaving medical treatment from a defective newborn.

Madam Justice Wilson, in her decision examined the right to liberty in s.7 of the Charter. She maintained that an essential component of the right to liberty "is the right to make fundamental personal decisions without interference from the state". [379] After extensively reviewing American jurisprudence which has carved out a zone of privacy with respect to certain fundamental personal decisions in areas involving education, child rearing, procreation, marriage, and contraception, as well as the right of a woman to terminate her pregnancy, she concluded: [380]:

> the respect for individual decisionmaking in matters of fundamental personal importance reflected in American jurisprudence also informs the Charter.

In reaching this conclusion, Madam Justice Wilson recognized a constitutionally protected right of privacy analogous to the right of privacy found in American constitutional law. This right has been held by American courts to encompass the right of an individual or a surrogate decisionmaker to refuse life-saving medical treatment under certain circumstances and it would clearly be open to Canadian courts to reach a similar conclusion in an appropriate case.[381]

Section 7 of the Charter also guarantees everyone the right to security of person. In their decision in Morgentaler, Chief Justice Dickson and Justice Beetz held that the right to security of the person protects the physical as well as the psychological integrity of the individual. Madam Justice Wilson shared this view and observed that:[382]

> State enforced medical or surgical treatment comes readily to mind as an obvious invasion of physical integrity.

Although the courts will order life-saving treatment for seriously ill and defective infants in the majority of cases on the basis that the infant's right to life is paramount, there are cases in which continued life cannot reasonably be said to be in an infant's best interest. In such cases, the courts could find continued life-sustaining medical treatment to be an infringement of the infant's right to security of person.[383]

The rights protected by s.7 of the Charter are not absolute. A person may only be "deprived" of these rights "in accordance with the principles of fundamental justice."

Lamer, J. analyzed the scope and content of the principles of fundamental justice in Re B.C. Motor Vehicle Act and observed that, at present "those words cannot be given any exhaustive content or simple enumerative definition, but will take on concrete meaning as the courts address alleged violations of s.7." [384]

However, in his opinion, these principles were to be construed broadly since "the narrower the meaning given to 'principles of fundamental justice', the greater will be the possibility that individuals will be deprived of these most basic [s.7] rights." [385] He therefore concluded that these principles are to be given a substantive as well as a procedural interpretation. Madam Justice Wilson concurred with this interpretation of the principles of fundamental justice in Morgentaler, stating: [386]

> The question is therefore whether the deprivation of the s.7 right is in accordance not only with procedural fairness but also with the fundamental rights and freedoms laid down elsewhere in the Charter.

She concluded that, "a deprivation of a s.7 right which has the effect of infringing a right guaranteed elsewhere in the Charter cannot be in accordance with the principles of fundamental justice."[387] Infringement of another constitutional right thus constitutes a breach of the principles of fundamental justice in a substantive sense.

It is submitted that current decisionmaking practices within Canadian neonatal units deny defective infants both substantive and procedural justice. First, there are no clearly identified criteria or guidelines which indicate under what conditions life-sustaining treatment may be withheld. Second, there are no clearly developed procedures governing the making of such decisions. In some cases, the parents decide alone, in others the physician decides alone and still in other cases, the decision is made jointly by parents and physicians. Ethics committees may provide support and guidance at some hospitals but are not available at others. However the decision is reached to withdraw life-saving treatment, what is clear is that these decisions are made on an ad hoc basis and infants with the same or similar conditions may be treated quite differently depending upon the parents' wishes, the doctor's beliefs or the hospital's policies. Such practices violate seriously ill and defective infants' equality rights under s.15 of the Charter which provides that "every individual ... has the right to equal protection ... without discrimination based upon age or physical or mental disability." Decisionmaking practices which violate infant's equality rights by failing to treat like-cases alike, are not in accordance with the principles of fundamental justice within the meaning of s.7 of the Charter. Moreover, it is unlikely that such practices would constitute a reasonable limit that is justified in a free and democratic society pursuant to s.1, given the fact that such infants are being deprived of the most fundamental right - the right to life.

If this analysis is correct, it must be asked what decisionmaking procedures would comply with the principle of procedural fairness in making life or death decisions for handicapped infants. Mr. Justice Lamer's comments in Re B.C. Motor Vehicles Act may provide an answer. He states: [388]

> ... the principles of fundamental justice are to be found in the basic tenents of our legal system. They do not lie in the realm of general public policy but in the inherent domain of the judiciary as guardian of the justice system. Such an approach to the interpretation of principles of

> fundamental justice "is consistent with the wording and structure of s.7, the context of the section, ... and the character and larger objects of the Charter itself. It provides meaningful content for the s.7 guarantee all the while avoiding adjudication of policy matters.

Justice Lamer's comments would seem to imply that such decisions should be left to the courts to determine and thus would appear to follow the non-delegation approach favoured by the majority of American state courts which have refused to delegate decisionmaking (except for narrowly defined categories of patients) to hospital ethics committees or like bodies.

In conclusion, it appears that it is now open to Canadian courts to find a right to refuse life-saving treatment under certain conditions based upon a constitutionally protected right of privacy which has now been recognized by the Supreme Court in Morgentaler. This right is similar to the American constitutional right of privacy first recognized in Quinlan which entitles a person, through a parent or guardian, to refuse life-saving medical treatment under certain circumstances.

V. Active Euthanasia

Active euthanasia is medically unethical and is illegal. A doctor who "intends" an infant's death and who "acts" to end the infant's life is guilty of murder under Canadian law.[389] His motive is irrelevant, for the law does not distinguish between homicides committed for reasons of vengeance or profit from those in which the actor's motive is one of mercy or compassion.[390]

Thus, a doctor may not administer a fatal overdose nor may he adminiser a lethal injection in order to relieve an infant's suffering, since he "intends" to cause the infant's death.

However, the law does permit the physician to "relieve pain." When a patient is suffering from a painful and incurable disease or is terminally ill, it is acceptable for doctors to administer narcotics or other pain-killing drugs to control pain. As the patient becomes habituated to the drug, it must be given in ever increasing doses to provide relief, though it is recognized that eventually the dosage required to relieve the pain will be fatal, if the patient has not already succumbed from other causes. The doctor is not guilty of murder in such cases since the drug is administered to ease pain, not to cause death.

There have been no reported cases in Canada in which a doctor has been prosecuted for (mercy) killing a patient. The Taschuk incident, discussed in the previous Chapter, would have been the first instance of such a case if the Crown had proceeded with the charges. As will be recalled, no charges were laid against the physician in question, since there was conflicting medical evidence as to whether the infant had died as a result of the overdose or from her pre-existing condition.[391] The Taschuk case illustrates the major practical difficulty in attempting to prosecute such cases -- causation. The prosecution must prove beyond a reasonable doubt that the doctor's act "caused" the infant's death. For seriously defective or terminally ill infants, this may be impossible to ascertain.

The lack of criminal proceedings against doctors for cases of active euthanasia has been suggested by the Law Reform Commission as reflective of "some ambiguity in the thinking and conduct of those responsible for the administration of the criminal justice system (witnesses, police officers, prosecutors, jurors, etc.)."[392] Thus, witnesses may choose not to report such cases, the police may be reluctant to lay charges, prosecutors may be reluctant to handle them and juries may be reluctant to convict.[393] However, societal tolerance cannot be assumed as the public outcry in the Taschuk case demonstrates. Society may be more willing to tolerate cases of compassionate murder where the "victim" is a terminally or incurably ill adult who wishes to die, than it would in the case of a helpless infant who cannot express an opinion and whose life has just begun.

VI. Conclusion

The law grants parents the right to make decisions regarding the medical treatment of their infant children and imposes a corresponding duty upon doctors to disclose to parents enough information to enable them to make an informed decision. This obligation requires physicians to discuss with the parents, the benefits and risks of proposed and alternative treatments as well as the consequences of foregoing treatment. The selective presentation of medical information to ensure parental compliance is not acceptable, though physicians are free to recommend the treatment choices they prefer. Mere presentation of the information may not be enough as physicians have an obligation to take reasonable steps to ensure that the parents understand the information that is given. The extent and scope of disclosure will vary with the circumstances in each case. Thus, inquisitive parents may require more detailed information, while in other cases, the parents may prefer to place greater reliance on the physician's recommendations without being advised in great detail.

Where physicians strongly disagree with parental decisions regarding medical treatment for their infant, they may not apply pressure on the parents to coerce them into making the decision the physician wants. Such tactics will vitiate any consent thereby obtained. However, the law provides physicians with mechanisms to obtain a valid consent to treat through child welfare statutes as well as by invoking the courts' inherent _parens patriae_ jurisdiction.

The courts in exercising their _parens patriae_ jurisdiction or authority under child welfare statutes, give primacy to the "best interests of the child." Familial considerations and the convenience of others may not outweigh this criterion, though the courts are cautious in overriding parental choices unless they are clearly not in the child's best interest.

Where an infant's life is merely of poor quality the courts will protect that life. There is a strong presumption in favour of life, but it is not absolute. If treatment can offer little hope of a cure and the treatment and/or the infant's condition causes great pain and suffering the courts will not order treatment. Similarly, there is some consensus that infants who are permanently comatose need not be given continued life-sustaining treatment.

In the United States, the right to be free of unwanted medical treatment has been given judicial recognition under the common law right to self-determination as well as a constitutional right to privacy. A similar right to privacy has recently been recognized by the Supreme Court of Canada in the Morgentaler case, which held that enforced medical treatment may in some circumstances be an infringement of the right to security of person under section 7 of the Charter.

Section 7 of the Charter also protects seriously ill and defective infants' right to life. However, s.7 rights are not absolute; a person may only be deprived of these rights in accordance with the principles of fundamental justice. This means that the courts would have to balance in a given case whether continued life was in an infant's best interests or not. In the majority of cases it will be, and in such cases the infant's right to life is paramount. However, in those rare cases in which it is not, (i.e., where the infant is comatose or suffering from irremediable pain) life-saving treatment could be considered an infringement of the infant's right to security of person and could thereby be terminated.

A somewhat artificial distinction is preserved in law between active and passive euthanasia. Physicians are permitted to relieve pain but are not permitted to intentionally end human life no matter how poor its quality or how great the suffering. Thus, gradually increasing quantities of pain-killers may be administered to relieve pain but administering a large enough dose to kill an infant to end its suffering is murder under Canadian law which recognizes intent but not motive.

The law imposes a duty upon parents and those having care of infants (including physicians) to provide them with the necessaries of life, which has been held to include medical treatment. Parents and physicians who refuse to or fail to provide medical treatment to seriously ill or defective infants may be criminally prosecuted. In addition, physicians may be civilly liable as well as being subject to disciplinary action by the College of Physicians and Surgeons and sanctions imposed by the hospital in which they hold privileges.

CHAPTER 2 ENDNOTES

1. Ellen I. Picard, *Legal Liability of Doctors and Hospitals in Canada*, 2nd ed. (Toronto, Carswell Legal Publications, 1984), p. 51; Allen M. Linden, *Canadian Tort Law*, 4th ed. (Toronto, Butterworth's, 1988), p. 57.

2. *Hopp v. Lepp* (1980) 13 C.C.L.T. 66, 73 (S.C.C.); *Reibl v. Hughes* (1980), 14 C.C.L.T. 1, 12-13 (S.C.C.); *Parmley v. Parmley* [1945] 4 D.L.R. 81 (S.C.C.); *Schloendorf v. Society of New York Hospitals* (1914), 211 N.Y. 125, 105 N.E. 92 (N.Y.C.A.).

3. *Mulloy v. Hop Sang* [1935], 1 W.W.R. 714 (Alta. C.A.). Linden, *supra* n.1 at 51.

4. Picard, *supra* n.1 at 25.

5. *Reibl v. Hughes, supra* n.2 at 13; *Sinclaire v. Boulton* (1985) 33 C.C.L.T. 125 (B.C.S.C.).

6. *Hopp v. Lepp, supra* n. 2 at 87.

7. *Reibl v. Hughes, supra* n.2 at 1.

8. *Supra* n.2 at 17-18.

9. *Zimmer v. Ringrose* (1981) 16 C.C.L.T. 51, 124 D.L.R. (3d) 215, 28 A.R. 69 (C.A.) [Leave to appeal to S.C.C. dismissed 37 N.R. 289]; *Schanczl v. Singh* (1987) 56 Alta. L.R. (2d) 303 (Q.B.); *Coughlin v. Kuntz* (1987) 17 B.C.L.R. (2d) 365 (S.C.); *Haughian v. Paine* [1987] 4 W.W.R. 97, 40 C.C.L.T. 13, 37 D.L.R. (4th) 624, 55 Sask. R. 99 (C.A.) [Leave to appeal to S.C.C. refused 1st October, 1987]; *Frerotte v. Irwin* (1986) 51 Sask R. 108 (Q.B.); *Ferguson v. Hamilton Civic Hospital* (1983) C.C.L.T. 254 (Ont. H.C.); aff'd (1985) 33 C.C.L.T. 56 (Ont. C.A.); *Sunne c. Shaw* [1981] C.S. 609 (Que.S.C.). *But see*, *Bucknam v. Kostuik* (1983) 44 O.R. (2d) 102 (H.C.); aff'd (1986) 55 O.R. (2d) 187 (C.A.); *Bonnell and Bonnell v. Gary Moddel, James E.N. Dickie and Scarborough General Hospital*, unreported, 5 February 1987, (Ont. H.C.); *Edwards v. Tucker*, unreported, 13 February, 1987 (Ont. H.C.).

10. Supra n.9.

11. Id. at 115.

12. Supra n.9.

13. Id. at 222.

14. Id. at 223.

15. Supra n.9.

16. Supra n.9.

17. Id. at 114.

18. Supra n.9.

19. Id. at 31.

20. Supra n.9 at 115.

21. Hopp v. Lepp, supra n.2 at 55.

22. Id., at 17, 59. See for example, Puranen v. Thompson (1987) 46 Man. R. (2d) 55 (Man. Q.B.) where non-disclosure by an anesthetist that a patient might be aware during surgery was held to be justified due to the patient's emotional state.

23. Smith v. Auckland Hospital Bd. [1964] N.Z.L.R. 241, reversed [1965] N.Z.L.R. 191 (C.A.).

24. Reibl v.Hughes, supra n.2 at 7; White v. Turner (1981) 31 O.R. (2d) 773, 15 C.C.L.T. 81, 120 D.L.R. (3d) 269 (H.C.J.).

25. Reibl v. Hughes, supra n.2 at 17. Ellen Picard recommends in such cases that the doctor should document the waiver and perhaps even have a witness. Supra, n.1 at 97, f.n. 398.

26. Reibl v. Hughes, supra n.2 at 59. See also, Kellett v. Griesdale, unreported, 26 June 1985, transcript judgment at p.11 (B.C.S.C.); Schanczl v. Singh (1987) 56 Alta. L.R. (2d) 303 at 313 (Q.B.).

27. Picard, supra n.1 at 111.

28. Reibl v. Hughes, supra n.2 at 10. See also Graham v. Persyko (1984) 30 C.C.L.T. (Ont.H.C.) where a breach of the duty of disclosure was found where a doctor failed to warn a patient of all the material risks associated with the use of a prescribed drug. The patient suffered a serious and permanent deterioration of the hip joints as a result of taking the drug. The Court found that had the patient been properly informed of the risks he would not have taken the drug.

29. Joseph Eliot Magnet and Eike-Henner W. Kluge, Withholding Treatment from Defective Newborn Children, (Cowansville, Que., Brown Legal Publications, 1985), p. 49. However, Justice Picard points out that in an action for battery "a Canadian court would have some difficulty assessing damages where a doctor by such a battery improved the health or prolonged the life of the patient. See Picard, supra n.1 at 52.

30. Picard, supra n.1 at 53.

31. Margaret Somerville, Consent to Medical Care, Protection of Life Series Study Paper, Law Reform Commission of Canada (Ottawa: Minister of Supply and Services, 1979), p.46.

32. Id., at 46. See, for example, Kelly v. Hazlett (1976) 15 O.R. (2d) 290, 317 (Ont.H.C.).

33. Somerville, supra n.31 at 47-48.

34. Parmley v. Parmley, supra n.2. The defendant dentist removed all of the patient's teeth although the patient had only consented to the removal of two teeth. Ree also Schweizer v. Central Hospital (1974) 6 O.R. (2d) 606, 53 D.L.R. (3d) 494 (H.C.) where the patient had consented to surgery on his toe but the defendant doctor performed a spinal fusion instead.

35. Picard, supra n.1 at 64.

36. Consent Form used by St. Joseph's Hospital in Toronto, cited in Linden, supra n.1 at 63.

37. Id., at 63. See also the cases Linden cites: Rogers v. Lumberman's Mutual (1960), 119 So. 2d 649; Valdez v. Percy (1939), 35 Cal. App. 2d 485, 96 P. 2d 142.

38. Pridham et al v. Nash Estate (1986) 57 O.R. (2d) 347, 33 D.L.R. (4th) 304 (sub nom Pridham v. Nash) (Ont.H.C.).

39. Brushett v. Cowan [1987] 42 C.C.L.T. 64 (Nfld. T.D.).

40. Id. at 69.

41. Picard, supra n.1 at 61-64. Picard points out that there are no statutory or judicial tests to measure such competency.

42. Id., at 55-60. See also, Somerville, supra n.31 at 71-75.

43. [1987] 2 W.W.R. 669 (C.A.).

44. Picard, supra n.1 at 58-60.

45. Alberta, Institute of Law Research and Reform, Report of the Institute of Law Research and Reform on the Consent of Minors to Health Care. Report No. 19 (Edmonton: Institute of Law Research and Reform, December, 1975), p. 10.

46. Criminal Code, R.S.C. 1970, c.-C34 [re-en. 1981-82-83, C.125, s.19].

47. Laporte v. Laganiere (1982) 18 C.R.N.S. 357, 361 (Que.Q.B.).

48. Law Reform Commission of Canada, Medical Treatment and Criminal Law, Protection of Life Series, Working Paper 26, (Ottawa: Minister of Supply and Services, 1980), p.18.

49. Id., at 18.

50. Id., at 18. See for example the Narcotic Control Act, R.S.C. 1970, c. N-1 and Alberta's Mental Health Act, S.A. 1980, c. M-13.

51. "There is a difference between consent and submission; every consent involves a submission; but it by no means follows, that a mere submission involves consent ..." See R. v. Day (1841) 9 C & P 722 at 724 (per Coleridge, J.) applied in R. v. Stinson (1934) 61 C.C.C. 227 (B.C.C.A.).

52. See R. v. Harms (1944) 2 D.L.R. 61 (Sask. C.A.), where the accused fraudulently represented that the act of sexual intercourse ws a necessary part of medical treatment and he complainant submitted because of the defendant's fraud. The accused was convicted of rape. In R. v. Case (1850) 1 Den. 580 (U.K.) on the same facts, a medical practitioner was convicted of assault since the court found the patient's acquiescence was due to the defendant's fraud. Bolduc v. Bird [1967] S.C.R. 667.

53. Law Reform Commission of Canada, supra n.48 at 66.

54. R. v. Carriere (1987) 56 L.R. (3d) 251 (Alta. C.A.).

55. Id. at 157. See Somerville supra n.31 at 106, who argues that sections 45 and 198 have the combined effect of making medical and surgical intervention legal.

56. Id., at 40. See also R. v. Morgentaler (No. 5) 47 D.L.R. (3d) 211, affirmed [1976] 1 S.C.R. 616, 53 D.L.R. (3d) 161 (S.C.C.).

57. Magnet and Kluge, supra n.29 at 55.

58. S.7(3) of the Criminal Code, R.S.C. 1970, c. C-34 as amended, preserves the common law defence of necessity.

59. Morgentaler v. The Queen [1976] 1 S.C.R. 616 (S.C.C.).

60. Perka v. The Queen (1984) 14 C.C.C. (3d) 385, [1984] 2 S.C.R. 232, 42 C.R. (3d) 113 (S.C.C.).

61. Supra n. 61 at 678.

62. Perka v. The Queen, supra n.62 at 233.

63. P.D.G. Skegg, "Consent to Medical Procedures on Minors," (1973) 36 Mod. L. Rev., 370 at 375.

64. Hopper v. Steeves (1899) 34 N.B.R. 591 (C.A.).

65. R.S.A. 1980, c. D-37.

66. Similar provisions exist in other provinces. For example, in British Columbia, the father and the mother are joint guardians of their child whether they are married or not as long as they live

together, unless a court of competent jurisdiction otherwise decides. s.27(1) Family Relations Act, R.S.B.C. 1979, c.21. In Manitoba, where the parents have never cohabited after the birth of their child, the parent with whom the child resides has sole custody and control of the child. s.14(1) Family Maintenance Act, (1978) Man., c. 25 (also C.C.S.M., c. F-20) [en. 1982-83-84, c. 54, s.19].

67. Supra n.68, s.46(a).

68. Re L. [1968] P.119, 132 (C.A.) per Omrod, J. "In normal circumstances the person who lawfully authorizes a physical interference with a child which might otherwise be technically in law an assault, is the parent of the child or some other person in whom parental rights are vested."

69. Saskatchewan: Hospital Standard Act, R.S.S. 1978, c. H-10, Sask. Reg. 331/79, s. 55. Apart from emergencies a parent or guardian's consent in writing must be obtained prior to performing a surgical operation on a person less than 18 years of age.

Manitoba: Private Hospitals Act, R.S.M. 1970, c. 206, C.C.S.M., c. P-130, Man. R. Reg., P-130, s. 6. Apart from an energency situation, no surgical operation may be performed on an individual in a private hospital without the consent in writing of the patient or his legally qualified representative.

Ontario: Public Hospitals Act, R.S.O. 1980, c. 410 (as amended), R.R.O. 1980, Reg. 865, s.50. No surgical operation shall be performed without a consent in writing being obtained from and signed by a parent or guardian or next of kin where a patient is less than 16 and is unmarried.

Quebec:

Public Health Protection Act, R.S.Q., c. P-35, s.42. Parental consent must be obtained where a minor is less than 14 in order to provide treatment. If consent cannot be obtained or is refused, a judge of the Superior Court may authorize treatment.

Health Services and Social Services Act, R.S.Q., c. S-5.

s.58 A person must sign a consent where a surgical operation is necessary, otherwise the hospital may refuse to treat unless there is an emergency.

s.66 Prior to administering an anaesthetic or performing a surgical procedure, a physician must ensure that the person on whom the operation is performed or his representative has given written consent and the physician must countersign the application form.

New Brunswick:

Public Hospitals Act, R.S.N.B. 1973, c. P-23. N.B. Reg. 84-212.

s.40 No surgical operation shall be performed on a patient unless consent in writing of the parent or guardian is obtained where a patient has not according to the provisions of the Medical Consent of Minors Act, reached the age of majority.

Medical Consent of Minors Act, S.N.B. 1976, c. M-6.1, s.3(1). If over age 16 a person can consent, however, a patient under 16 can consent if in the opinion of 2 legally qualified medical practitioners he is able to understand the nature and consequences of the procedure and the treatment is in his best interests.

70. For a good discussion of the necessity doctrine in civil law, see P.D.G. Skegg, "A Justification for Medical Procedures Performed Without Consent," (1974) 90 L.Q.R. 512-530.

71. [1933] 3 D.L.R. 260 (N.S.S.C.).

72. Id., at 275.

73. [1949] 2 D.L.R. 442 (B.C.S.C.).

74. Id., at 444-45. See also Parmley v. Parmley [1945] 4 D.L.R. (S.C.C.) where doctor and dentist removed all of a patient's teeth (consent being given to removal of two). The court found that it was convenient but not necessary to remove all of the patient's teeth.

75. (1975) 53 D.L.R. 494 (Ont. H.C.).

76. Id., at 507.

77. [1935] 1 W.W.R. 714 (AIta. S.C.A.D.).

78. (1987) 43 C.C.L.T. 62 (Ont.H.C.).

79. Hospital Standard Act, R.S.S. 1978, c. H-10, Sask Reg. 331/79, s.55(2).

80. Law Reform Commission of Saskatchewan, Tentative Proposals for a Consent of Minors to Health Care Act, November, 1978, p. 26.

81. Id., s.5(1).

82. Id., s.5(2).

83. Institute of Law Research and Reform, University of Alberta, Consent of Minors to Health Care, Report No. 19, s.5(1), p. 63.

84. Id., s.5(2), p. 63.

85. Sections 3(1)(2), 4(1).

86. Private Hospitals Act, R.S.M. 1970, c. 206, C.C.S.M., c. P130, Man. R. Reg. 1971, Reg. P130-R.1, s.6(2)(a).

87. Id., s.6(2)(b).

88. Id., s.6(4).

89. The Public Hospitals Act, R.S.O. 1980, c. 410. R.R.O. 1980, Reg. 865, s.50.

90. Id., s.50(d)(e).

91. (1986) 31 D.L.R. (4th) 1.

92. Public Health Protection Act, R.S.Q. 1977, c. P-35.

93. Supra n. 29 at 56.

94. "Responsibilities to the Patient," (December, 1984), art. 14.

95. Supra, n. 29 at 54.

96. In Alberta, older children and adolescents who have the capacity to understand the purpose and consequences of treatment may consent to treatment

themselves. See Picard, supra n.1 at 55.

97. Bernard M. Dickens, "The Modern Function and Limits of Parental Rights," (1981) 97 L.Q.R. 462.

98. Id., at 471. Professor Dickens' remarks quoted with approval in Re Wintersgill (1981) 131 D.L.R. (3d) 184 (Sask. U.F.C.).

99. Id., at 472.

100. Id., at 472. See Re Eve (1986) 31 D.L.R. (4th) 1.

101. Id., at 472. See for example, Custody of a Minor (1979), 393 N.E. 2d 836 (Mass. Sup. Jud. Ct.). The Court ordered chemotherapy to be given over the parents objections as the parent's choice of laetrile was found to be both ineffective and harmful.

102. Supra n. 101.

103. Id., at 199. See also, Re R.K. (1987') 79 A.R. 140, 144 (Alta. Prov. Ct.) in which Carter, J. s comments were cited with approval.

104. S.A. 1984, c. C-8.1, s. 1(2)(c).

105. British Columbia: Family and Child Service Act, S.B.C. 1980, c.11, s.1.

Saskatchewan: The Family Services Act, R.S.S. 1978, c. F-7, s. 15(d)(e).

Manitoba: The Child and Family Services Act, S.M. 1985-86, c.8 - C.80, s.17(b)(ii)(ii).

Ontario: Child and Family Services Act, S.O. 1984, c.55, s.37(2)(e).

Quebec: Youth Protection Act, S.Q. 1977, c. P-34.1, as amended by S.Q. 1984, s.38(c).

New Brunswick: Child and Family Services and Family Relations Act, S.N.B. 1980, c. C-2.1, s.31(1).

Nova Scotia: Children's Services Act, S.N.S. 1976, c.8, s.2(m)(iv)(vii).

Newfoundland: Child Welfare Act, S.N. 1972, No. 37, as amended by S.N. 1981, c.54, s.2(ix).

Prince Edward Island: Family and Child Services Act, S.P.E.I. 1981, c.12, s.1(2)(f).

106. Supra n. 108, s.37(h).

107. Alberta: Child Welfare Act, R.S.A. 1984, c.C-8.1, s.17(1).

British Columbia: Family and Child Service Act, S.B.C. 1980, c.11, s.9(1)(2)(3).

Saskatchewan: The Family Services Act, R.S.S. 1978, c. F-7, s.20(1).

Manitoba: The Child and Family Services Act, S.M. 1985-86, c.8 - C.80, s.21(1).

Ontario: Child and Family Services Act, S.O. 1984, c.55, s.40(2)(6).

Quebec: Youth Protection Act, S.Q. 1977, c. P-34.1, as amended by S.Q. 1984, c.4, s.33, 33.1, 33.3.

New Brunswick: Child and Family Services and Family Relations Act, S.N.B. 1980, c. C-2.1, s.32(1), 51(1).

Nova Scotia: Children's Services Act, S.N.S. 1976, c.8, s.45(1).

Newfoundland: Child Welfare Act, S.N. 1972, No. 37, s.11(1), as amended.

Prince Edward Island: Family and Child Services Act, S.P.E.I. 1981, as amended by S.P.E.I. 1982, c.8, s.15(1).

108. Child Welfare Act, R.S.A. 1984, c. C-8.1, s.20(1)(a). Similar provisions are found in:

British Columbia: Family and Child Service Act, S.B.C. 1980, c.11, s.10(1)(b).

Saskatchewan: The Family Services Act, R.S.S. 1978, c. F-7, s.43(3).

Manitoba: The Child and Family Services Act, S.M. 1985-86, c.8 - c.80, s.25(1)(b).

Quebec: Youth Protection Act, S.Q. 1977, c. P-34.1, ss.45, 47, 48 as amended by S.Q. 1984, c.4, ss. 21, 23, 24.

New Brunswick: Child and Family Services and Family Relations Act, S.N.B. 1980, c. C-2.1, s.32(2)(b).

Nova Scotia: Children's Services Act, S.N.S. 1976, c.8, s.45(3).

Newfoundland: Child Welfare Act, S.N. 1972, No. 37, s.11(5)(6), as amended.

Prince Edward Island: Family and Child Services Act, S.P.E.I. 1981, c.12, s.25(a)(c).

109. Youth Protection Act, S.Q. 1977, c.P-34.1, s.47, as amended by S.Q. 1984, c.4, s.23.

110. Id., S.Q. 1984, c.4, s.27.

111. Supra n.108, s.40(8).

112. Family and Child Services Act, S.P.E.I. 1981, c.12, s.25(b)(c).

113. Supra, n. 111. [excluding Quebec, Ontario and Prince Edward Island].

114. Child Welfare Act, S.A. 1984, c. C-8.1, s.20(2).

115. Id., s.20(3)(4). See Ontario Child and Family Services Act, S.O. 1984, c.55, s.39(7).

116. Id., s.19(2). See B.C. Family and Child Services Act, S.B.C. 1980, c.11, s.11. Report and hearing must be held not later than 7 days after the child is apprehended.

117. Id., s.20(5).

118. Id., s.20(6).

119. David R. James. "Child Medical Neglect and Surgical Procedures: The Respective Obligations of Parent, Doctor and Child Care Agency," (1986) 7 Health L. Can., 14 at 16.

120. Alberta: Child Welfare Act, S.A. 1984, c. C-8.1, s.s.29(1), 32(1). The Court may appoint a Children's Guardian as guardian of a child. Temporary guardianship is for a period of not more than one year. s.29(1).

British Columbia: Family and Child Services Act, S.B.C. 1980, c.11, s.s.13 and 14. Temporary or permanent custody given to the superintendent of the Children's Aid Society.

Saskatchewan: The Family Services Act, R.S.S. 1978, c. F-7, s.29(b)(b). Temporary or permanent committal to the Minister of Social Services.

Manitoba: The Child and Family Services Act, S.M. 1985-86, c.8 - C.80, s.38(c)(f). Temporary or permanent guardianship to the child and family services agency.

Ontario: Child and Family Services Act, S.O. 1984, c.55, s.53(1), Paragraph 2.

> The child may be made a temporary ward of the Children's Aid Society. s.58(1) The Society may then consent to any medical treatment the child might require, unless the court orders that the parent shall retain the right to consent or refuse medical treatment. s.58(2) The court shall not make an order under subsection (1) where the parent's failure to consent was a reason for finding the child in need of protection. s.58(3) Where the parent refuses or is unavailable or unable to consent to medical treatment for the child and the Court is satisfied that treatment would be in the child's best interests, the Court may authorize the Society to consent to treatment.

s.53(1), Paragraph 3.

> A child may be made a temporary or permanent ward of the Crown. S.59(1) Where a child is made a Crown ward the Crown has the right to give or refuse medical treatment for the child where a parent's consent would otherwise be required.

Quebec: Youth Protection Act, S.Q. 1977, c. P-34.1, ss. 54(c), 62. No provision is made for wardship, rather the parents may voluntarily agree that the child be entrusted to other persons or the Court may order the compulsory foster care of a child.

New Brunswick: Child and Family Services and Family Relations Act, S.N.B. 1980, c. C-2.1, ss. 55(1), 56(1). Guardianship may be transferred to the Minister of Social Services on a temporary or permanent basis.

Nova Scotia: Children's Services Act, S.N.S. 1976, c.8, s.49(c)(ii). The child may be committed to the care of an agency, (s.51) either temporarily or permanently.

Newfoundland: Child Welfare Act, S.N. 1972, No. 37, s.15(1)(c). The child may be committed temporarily or permanently to the custody of the director.

Prince Edward Island: Family and Child Services Act, S.P.E.I. 1981, c.12, s.34(2)(b)(c). The child may be committed temporarily or permanently to the custody or guardianship of the Director of Child Welfare.

121. British Columbia: Family and Child Services Act, S.B.C. 1980, c.11, s.2. The safety and well-being of the child shall be the paramount considerations. But see Re K. (1982) 133 D.L.R. (3d) 509, 36 B.C.L.R. 269 (B.C.S.C.) - although the safety and well-being of the child is the paramount consideration, it is not the only consideration.

Saskatchewan: The Family Services Act, R.S.S. 1978, c. F-7, ss. 46, 47 deal with the return of the child to the parents and the Minister's power to enter into certain contracts respecting the child. Both sections refer to the child's interests or best interests. See also Re Anderson (1978) 6 R.F.L. (2d) 169, aff. (sub. nom. Anderson v. Ross) 10 R.F.L. (2d) 286, 3 Sask. R. 271 (C.A.). In dispensing with a parents consent (to adoption ss. 53, 54 of the Act) the court held that the sole criterion is the "best interests of the child".

Manitoba: The Child and Family Services Act, S.M. 1985-86, c.8 - C.80, Declaration of Principles No. 9. Decisions to remove or place children should be based on the best interests of the child ..., s.2 The best interests of the child shall be the paramount consideration ... in any proceedings under this Act affecting a child, other than proceedings to determine whether a child is in need of protection, and in determining the best interests of the child all relevant matters shall be considered, including: (here the statute lists a number of criteria to be considered, the most important being) (b) the mental, emotional, physical and educational needs of the child and the appropriate care or treatment, or both, to meet such needs. (emphasis added).

Ontario: Child and Family Services Act, S.O. 1984, c.55, s.37(3). In making an order or determination in the best interests of the child, the decisionmaker shall take into consideration those of the following circumstances of the case that he or she considers relevant: No.'s 1 & 12: which consider the child's physical, mental and emotional needs and the appropriate care or treatment to meet those needs, and the degree of risk, if any, that justified the finding that the child is in need of protection.

Quebec: Youth Protection Act, S.Q. 1977, c. P-34.1, s.3 as amended by S.Q. 1984, c.4, s.4. Decisions made under this Act must be in the interest of the child and respect his rights.

New Brunswick: Child and Family Services and Family Relations Act, S.N.B. 1980, c. C-2.1, s.1(a) "best interests of the child" means ... taking into consideration the mental, emotional and physical health of the child and his need for appropriate care or treatment, or both.

Nova Scotia: Children's Services Act, S.N.S. 1976, c.8, s.49(1)(c)(i). When a court returns a child to the parents under an order for friendly supervision it shall consider the "best interests of the child". However, there is no such requirement when committing the child to the care of the child welfare agency. But see, C.A.S. v. Maguire (1979) 9 C.P.C. 220, 228 (N.S.S.C.) where the Court considered the best interests of the child in deciding to award custody to the C.A.S.

Newfoundland: Child Welfare Act, S.N. 1972, No. 37, s.2.1(1) as amended by S.N. 1981, c.54, s.3. The paramount consideration in a determination under this Act with respect to a child in need of protection is the best interests of that child. A number of factors for consideration are enumerated including (c) the necessity for appropriate care or treatment or both for mental, emotional or physical health of the child.

Prince Edward Island: Family and Child Services Act, S.P.E.I. 1981, c.12, s.1(1)(d) "best interests of the child" means the best interests of the child under all the circumstances, having regard, in addition to all other relevant considerations, to (A number of factors are listed including) ... (ii) the mental, emotional and physical health of the child including any special needs for care and treatment.

122. S.A. 1984, c.C-8.1.

123. *Supra*, n. 107.

124. *Re L.D.K.; C.A.S. v. K and K* (1985) 48 R.F.L. (2d) 164 (Ont. Prov.Ct.). Ontario's Child Welfare Act defined a child "in need of protection" as one whose guardian neglected or refused to provide proper medical or surgical or other recognized remedial care or treatment necessary for the child's health and well-being. Where an alternative treatment was recommended by another physician and was available it could not be said that the child was being denied 'proper' medical treatment and the Society failed to discharge the onus that the child was in need of protection.

125. *Supra* n.29 at 69.

126. *Supra* n.25.

127. *Supra* n.106.

128. Id., at 144.

129. Id., at 144.

130. Id., at 145.

131. (1986) 47 Alta. L.R. (2d) 380 (Alta. Q.B.).

132. Id., at 389. The trial judge's remarks are quoted from the appeal judgment.

133. Id., at 389-390.

134. *Re Wintersgill* 1981) 15 Sask. R. 435 (U.F.C.).

135. Bernard M. Dickens, "Comment on the Dawson Case," (1984) 62 *Can. Bar. Rev.* 204-205. See Chapter One discussion of economic considerations.

136. *Beverly's Case* (1603) 4 Co. Rep. 123(b), 76 E.R. 1118, 1124.

137. *Wellesley v. Duke of Beaufort* (1827) 2 Russ. 1, 38 E.R. 236, at 243.

138. *Cary (Lord Falkland) v. Bertie* (1696) 2 Vern. 333, 342, 23 E.R. 814, 818.

139. *Supra*, n.103, at 14.

140. Id., at 28. See also *Re Lutz et al and Legal Aid Manitoba* (1982) 138 D.L.R. (3d) 385, 29 R.F.L. (2d) 337, 21 Alta. L.R. (2d) 345 (Alta. C.A.). McDermid,

J.A. stated at p.387 D.L.R.: In addition to the provisions under the Child Welfare Act giving jurisdiction to the court to grant guardianship orders of custody and control, the Alberta Courts have the parens patriae jurisdiction exercised by the Court of Chancery in England.

141. Re X (a minor) [1975] 1 All E.R. 697, 699 (Fam. D.).

142. Supra, n.103 at 28.

143. Id., at p. 29.

144. In re S.D. (1983) 3 W.W.R. 618 (B.C.S.C.).

145. Supra n.103.

146. Supra n.144 at 704 and 706.

147. Id., at p.706.

148. Re L. [1968] 1 All E.R. 20 (C.A.).

149. Supra n.103.

150. Id., at 29.

151. Id., at 31.

152. Id., at 32.

153. Supra n.147.

154. Supra n.103, at 32.

155. Id., at 30.

156. Id., at 32.

157. Id., at 31.

158. Strunk v. Strunk (1969) 445 S.W. 2d 145.

159. Supra n.103 at 29.

160. Supra n.29 at 128.

161. Child Welfare Act, S.A. 1980, c.C-8.1, s.1(2)(c).

162. S.B.C. 1980, c.11, s.2.

163. M. (R.E.D.) v. Dir. of Child Welfare (1986) 47 Alta. L.R. (2d) 380, 389-390 (Alta. Q.B.).

164. Supra n.106 at 147.

165. Supra n.1 at 200.

166. See Beninger v.Walton [1979] B.C.D. Civ. 2632-02 (B.C.S.C.) cited in Picard, supra, n.1 at 200.

167. (1983) 26 Atla. L. Rptr. cited in Michael D. Volk and Melvin D. Morgan, Medical Malpractice: Handling Obstetric and Neonatal Cases (Colorado Springs: Shepard's McGraw Hill, 1986), p.p. 794-95.

168. Supra n.1 at 210-211.

169. Id., at 212.

170. C.M.A. Code of Ethics (December, 1984), art. 4.

171. Id., art. 39.

172. Id., art. 40.

173. Hospitals Act, R.S.A. 1980, c.H-11, s.32(4) requires the medical staff by-laws be approved by the Minister of Health.

174. Foothills Provincial General Hospital, Medical Staff By-Law, s.30.10.

175. Foothills Provincial General Hospital, Rules and Regulations, s.14.0.

176 Id., s.14.0.

177. Supra n.1 at 4.

178. C.M.A. Code of Ethics (December, 1984), art. 15.

179. Id., art. 5.

180. Criminal Code, R.S.C. 1970, c.C-34, as amended,

Section 202:

(1) Everyone is criminally negligent who

(b) in omitting to do anything that is his duty to do, shows wanton or reckless disregard for the lives or safety of other persons

(2) For the purposes of this section, "duty" means a duty imposed by law.

Section 203:

Every one who by criminal negligence causes death to another person is guilty of an indictable offence and is liable to imprisonment for life.

Section 204:

Every one who by criminal negligence causes bodily harm to another person is guilty of an indictable offence and is liable to imprisonment for ten years.

181. Section 205 provides:

(5) A person commits culpable homicide when he causes he death of a human being

(b) by criminal negligence.

182. Supra n.29 at 119. However, the physicians may be required to consult with another doctor in such cases by the by-laws of the hospital in which he has privileges. See Foothills Hospital's Regulations discussed supra n.178.

183. Supra, n.48 at 1.

184. For example, in an unreported English case R. v. Arthur a charge of murder (later reduced to attempted murder) was laid against a pediatrician who prescribed a regimen of 'nursing care' consisting of providing a sedating drug but no food to a mongoloid infant.

185. Vale v. R. J. Yohn Construction Co. Ltd. (1970) 12 D.L.R. (3d) 465; L1970] 3 O.R. 137 (Ont.C.A.).

186. Kleisinger v. Diminyatz [1937] 3 W.W.R. 481, 491 (Sask. C.A.). No damages were awarded for the loss of a child of two. Pedlar v. Toronto Power Co. (1913) 20 O.L.R. 527; aff'd 30 D.L.R. 581 (C.A.). The Court commented that the damages in the case of a child aged two might by reason of the uncertainties and contingencies of life be reduced to the vanishing point. Alaffe v. Kennedy (1973) 40 D.L.R. (3d)

429, (N.S.S.C.). The Court found it was impossible to demonstrate any reasonable expectation of pecuniary benefit in the case of a 4 month old infant.

187. S.A. 1980, c.F-5, s.8(2)(b).

188. Robitaille v. Vancouver Hockey Club Ltd. (1979) 19 B.C.L.R. 158, 180,; aff'd (1981) 16 C.C.L.T. 225 (B.C.C.A.).

189. Foothills Provincial General Hospital, Medical Staff By-Law, s.30.6.

190. R.S.A. 1980, c.M-12, s.34(1)(a).

191. Id., s.34(1)(b).

192. Id., s.56(1)(a)-(d). Re Reich and College of Physicians and Surgeons (1984) 8 D.L.R. (4th) 691, 53 A.R. 321 (Alta.Q.B.). The Council of the College of Physicians and Surgeons can do only one of the four things mentioned in s.56(1), thus it cannot impose both a suspension and a reprimand.

193. Id., s.56(2).

194. Matter of Quinlan, 305 A. (2d) 647, 70 A.J. 10 355 A. (2d) 647 (N.J. 1976). See also: George Annass "In re Quinlan: Legal Comfort for Doctors," (1976) 6 Hastings Center Report 29; H.R. Beresford, "The Quinlan Decision: Problems and Legislative Alternatives." (1977) 2 Annals of Neurology 74;

Norman L. Cantor, "Quinlan, Privacy, and the Handling of Incompetent Dying Patients," (1977) 30 Rutgers L. Rev. 243; Harold L. Hirsch and Richard E. Donovan, "The Right to Die: Medico-Legal Implications of In Re Quinlan," (1977) 30 Rutgers L. Rev. 267.

195. Quinlan, supra n.97 at 653.

196. Id., at 652.

197. Id., at 655.

198. Id., at 663.

199. Id., at 663. The earlier decisions the Court referred to were: Griswold v. Connecticut, 381 U.S. 479, 85 S. Ct. 1678, 14 L. Ed. (2d) 510 (1965) and Roe v. Wade, 410 U.S. 113, 93 S. Ct. 705, 35 L. Ed. (2d) 147 (1973).

200. Id., at 664.

201. Id., at 664.

202. Id., at 665.

203. The Court also pointed out that the principles it enunciated in this case might well apply to other types of terminal medical illnesses.

204. See, for example: Eichner v. Dillon, 426 N.Y.S. (2d) 517 (App. Div. 1980), aff'd (sub. nom. Matter of Storar) 438 N.Y.S. (2d) 266, 420 N.E. (2d) 64 (1981); Matter of Dinnerstein, 380 N.E. (2d) 134 (Mass. App. Ct. 1978); Matter of Colyer, 660 P. (2d) 738 (Sup. Ct. Wash. 1983).

205. See, for example, Matter of Storar, supra n.207, at 273.

206. In Re Guardianship of Barry, 445 So. (2d) 365 (Fla. Dist. App. Ct. 1984). The Court permitted the withdrawal of life-support measures on a ten month old infant with no brain function based on a constitutional right of privacy. A number of American legal commentators have reached this conclusion: Donald G. Collester, Jr., "Death, Dying and the Law: A Prosecutorial View of the Quinlan Case," (1977) 30 Rutgers L. Rev. 304 at 323; Larry Gostin, "A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates," (1985) 2 Am. J. L. and Med. 31, at 42; David W. Meyers, Medico-Legal Implications of Death and Dying, (Rochester, New York: The Lawyer's Cooperative Publishing Co.), p.445. Other commentators disagree: See T.S. Ellis, "Letting Defective Babies Die: Who Decides?", (1982) 7 Am. J.L. and Med. 393 at 406.

207. La. Rev. Stat. Ann. ss 1299.36.1 (West. Supp. 1983).
211. In re P.V.W., 424 So. (2d) 1015 (Sup. Ct. La.).

208. In re P.V.W., 424 So. (2d) 1015 (Sup. Ct. La.).

209. Superintendent of Belchertown State School et al v. Joseph Saikewicz 370 N.E. (2d) 417 at 421 (Mass. Sup. Jud. Ct. 1977).

210. Id., at 421.

211. Id., at 427.

212. Id., at 430.

213. Id., at 430-431. But see George J. Annas, "Help from the Dead: The Cases of Brother Fox and John Storar," (1981) 11 Hastings Center Report 19. Annas argues that the substituted judgment is applicable to previously competent patients but not to patients who have always been profoundly retarded.

214. Id., 430-431.

215. Supra n.29 at 88-89 and 137-38.

216. Supra n.212 at 425-426.

217. Matter of Dinnerstein, 380 N.E. (2d) 134 (Mass. App. Ct. 1978).

218. Id., at 135-36.

219. Matter of Spring, 399 N.E. (2d) 493 (Mass. App. Ct. 1979) rev'd on other grounds 405 N.E. (2d) 115 (Mass. 1980).

220. Id., at 502.

221. Custody of a Minor, 385 Mass. 697, 434 N.E. (2d) 601 (Mass. Sup. Jud. Ct. 1982).

222. Id., at 604.

223. Id., at 607.

224. Id., at 610.

225. Matter of Storar, 438 N.Y.S. (2d) 266, N.E. (2d) 64 (N.Y. C.A. 1981).

226. Id., at 275. See Annas, supra n.216.

227. Id., at 275.

228. Id., at 275.

229. Id., at 275-76.

230. Id., at 275. Although the Court mentioned that the transfusions did not involve excessive pain they specifically left open the question of whether excessive pain would have been determinitive with respect to the continuation of a life-sustaining mesure holding that it did not have to be determined under the facts of this case. However, the majority opinion's finding that Storar's "quality of life" would be improved by the transfusions was strongly disputed by one of the two dissenting judges. Mr.

Justice Jones was of the view that the evidence supported the opposite conclusion. He noted (at p.280) that, with the transfusions, Mr. Storar's behavior changed - he rarely left his room, he became progressively uncomfortable during the procedures, urination became more painful and he had heightened sensitivity to the pain of cancer. Without the transfusions he suffered no additional pain; cessation of the transfusions might lessen his sensitivity to pain sensations and lead to a subsiding of bleeding from his lesions. Given these findings, Jones, J. concluded that, in this case, the treatment would be extraordinary and that his mother who loved him could decide his best interests.

231. *Supra* n.29 at 94-95. *See also*, George J. Annas, "Help from the Dead: The Cases of Brother Fox and John Storar," (1981) 11 *Hastings Center Report* 19.

232. *In the Matter of Baby F*. (1983) Coos County (Ore.) Circuit Court No. J38 involved an infant born with occipital encephalocele in which a portion of the brain is outside of the skull along with other multiple abnormalities. The Court held that there was no obligation to institute intravenous feeding or other life-support treatments that would not alter the terminal prognosis.

233. Steven R. Smith, "Life and Death Decisions in the Nursery Standards and Procedures for Withholding Lifesaving Treatment from Infants," (1981-82) 27 *N.Y. L. Sch. L. Rev.* 1125-86, 1132.

234. *United States v. Orito*, 413 U.S. 139, 142, 93 S. Ct. 2674, 37 L. Ed. (2d) 513 (1973).

235. *Wisconsin v. Yoder*, 406 U.S. 205, 232, 92 S. Ct. 1526, 32 L. Ed. (2d) 15 (1972). Parents have a fundamental interest to guide the religious future and education of their children; *Pierce v. Society of Sisters* 268 U.S. 510, 534-34, 45 S. Ct. 571, 69 L. Ed. 1070 (1925). Parents have a right to direct the education of their children.

236. *Prince v. Massachusetts*, 321 U.S. 158, 166, 64 S. Ct. 438, 88 L. Ed. 645 (1944).

237. Id., at 166-67. In *Wisconsin v. Yoder*, *supra* n. 225 at 223-24, the Court held that "the power of the parent ... may be subject to limitation under *Prince* if it appears that parental decisions will jeopardize the health or safety of the child...".

238. In re Phillip B., 92 Cal. App. (3d) 796, 799 (1979), cert. denied, 445 U.S. 949 (1980).

239. Custody of a Minor, 379 N.E (2d) 1053 (Mass. Sup. Jud. Ct. 1978).

240. Id., at 1063.

241. Id., at 1065.

242. Application of Cicero, 101 Misc. (2d) 699, 421 N.Y.S. (2d) 965 (Bronx County Sup. Ct. 1979).

243. Id., at 967-68.

244. In re Elin Daniels, No. 81-15577FJ01 (Cir. Dade County, June 23, 1981). The case is discussed in Carmen Portela, "The Elin Case: An Examination of the Legal, Medical and Ethical Considerations Posed When Parents and Doctors Disagree on Whether to Treat a Defective Newborn," (1983) 18 FORUM 709.

245. Id., at 711.

246. In re Jeff and Scott Mueller, Nos. 81J300 and 81J301 (5th Cir. May 15, 1981). The case is discussed in the following articles: John A. Robertson, "Dilemma in Danville," (1981) 11 Hastings Center Report 5; Sheila Taub, "Withholding Treatment from Defective Newborns," Law, Med and Health Care, 4; and in Robert F. Weir, Selective Non-Treatment of Handicapped Newborns Moral Dilemmas in Neonatal Medicine, (New York and Oxford Oxrord University Press, 1984), p.p. 95-97.

247. Taub, supra n. 249 at 4.

248. Robertson, supra n. 249 at 5; Weir, supra n. 249 at 96-97.

249. Taub, supra n. 249 at 4.

250. Maine Medical Center v. Houle No. 74-145 (Maine Sup. Ct. Feb. 19, 1974). The case is reprinted in Robert Weir, ed., Ethical Issues in Death and Dying, 2nd ed. (New York: Columbia University Press, 1977), p.p. 185-186.

251. Id., at 186.

252. Collester, Jr., supra n. 209 at 323.

253. Weir, supra n. 253 at 186.

254. Supra n. 29 at 195.

255. Supra n. 241.

256. Id., at 799.

257. George Annas, "Denying the Rights of the Retarded: The Phillip Becker Case," (1979) 9 Hastings Center Report 18 at 20. Larry Gostin, "A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates," (1985) 2 Am. J. L. and Med. 31 at 52, f.n. 58.

258. John A. Robertson, "Legal Aspects of Withholding Medical Treatment from Handicapped Children," in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, edited by A. Edward Doudera and J. Douglas Peters, (Ann Arbor, Michigan: AUPHA Press, 1982), p. 222; Gostin, supra n.260 at 52.

259. Infant Doe v. Bloomington Hospital, No. G.U 8204-00 (Ind. Monroe Co. Cir. Ct. 1982); cert. denied (U.S.) 104 S. Ct. 394. This case is discussed in greater detail in Chapter Five.

260. This may not be correct. One legal commentator, Steven R. Smith, a professor of law at Louisville, was advised by the assistant administrator of the court that the infant had multiple defects in addition to the atresia, and that a guardian ad litem had been appointed who had "declined to join in an effort to overturn the decision to withhold treatment." Furthermore, a six member task force reviewed and concurred with the decision. Smith concludes that "this suggests that a significant review process was employed by the physicians, hospital or courts." See Smith, supra n. 236 at 1137, f.n. 41.

261. Matter of Hofbauer, 47 (2d) 648, 411 N.Y.S. (2d) 416, 393 N.E. (2d) 1009 (N.Y. Ct. Apps. 1979).

262. Id., at 418.

263. Weber v. Stony Brook Hospital, 95 A.D. (2d) 587, 467 N.Y.S. (2d) 685 (N.Y. App. Div. 1983).

264. Id., at 687.

265. Supra n. 242. See also Custody of a Minor, 393 N.E. (2d) 836 (Mass. Sup. Jud. Ct. 1979).

266. See _Cicero, supra_ n. 245 (low-lesion, spina bifida); _Daniels, supra_ n. 247 (high-lesion, more serious, spina bifida); _contra, Becker, supra_ n. 241 (but Becker is generally considered to be wrongly decided).

267. _Supra_ n. 253.

268. _Hofbauer, supra_ n. 264 (parental choice for conservative treatment for Hodgkins disease permitted); _Weber, supra_ n. 266 (parental choice for conservative treatment for child with microencephaly and spina bifida permitted).

269. _Dinnerstein, supra_ n. 207.

270. _Supra_ n. 222 at 503.

271. _In the Matter of Nancy Ellen Jobes_, No. A-108/109 (N.J. June 24, 1987). The case is discussed in _BIO LAW_. _A Legal and Ethical Reporter on Medicine, Health Care and Bioengineering_. Vol. 1 (Frederick, M.D.: University of Publications of America, 1987), p. U:578.

272. _See, for example_: _Quinlan, supra_ n. 197; _Saikewicz, supra_ n. 212; _Eichner, supra_ n. 207.

273. _Supra_ n. 197 at 667-68.

274. _Barber v. Superior Court of the State of California_, 195 Cal. Rptr. 484 (Cal. App. 2 Dist. 1983).

275. Id., at 491.

276. Id., at 492.

277. _Supra_ n. 197 at 669.

278. Id., at 669.

279. Id., at 671-72.

280. _Supra_ n. 207.

281. Id., at 746.

282. Id., at 749.

283. Id., at 750.

284. _Supra_ n. 212.

285. Id., at 435.

286. George G. Annas, "Reconciling Quinlan and Saikewicz: Decisionmaking for the Terminally Incompetent," (1979) 4 Am. J. L. and Med. 367. See also, "Letter to the Editor", from Barnes and Others (1978) 298 New Eng. M. Med. 516-17.

287. Supra n. 207.

288. Id., at 138.

289. Id., at 139.

290. Supra n. 222, at 120.

291. Id., at 120.

292. Id., at 121.

293. Id., at 122.

294. Id., at 122.

295. Supra n. 207.

296. Id., at 550.

297. Id., at 550.

298. Matter of Storar, 438 N.Y. (2d) 266, 276 (Ct. App., 1981).

299. Supra n. 277, at 493.

300. Supra n. 211 at 1020.

301. In re B. (A Minor) [1981] 1 W.L.R. 1421 (C.A.). See the discussion of Re B by the C.A. in McKay v. Essex Health Authority and Another [1982] 2 W.L.R. 890 at 909.

302. Id., at 1422.

303. Id., at 1422.

304. The decision was unreported, however, it was reviewed in The Times, November 6, 1981 at 1, 12 and has been widely discussed. See for example: Diana and Malcolm Brahams, "The Arthur Case - A Proposal for Legislation," (1983) 9 J. Med. Ethics, 12; John Havard, "Legislation Is Likely To Create More Difficulties Than It Resolves," (1983) 9 J. Med. Ethics 18; J. K. Mason and R. A. McCall-Smith, Law and Medical Ethics, 2nd ed. (London: Butterworth &Co. (Publishers) Ltd., 1987), p.p. 84-85; J.K. Mason and David W. Meyers, "Parental Choice and Selective

Non-Treatment of Defective Newborns A View From mid-Atlantic," (1986) 12 *J. Med. Ethics* 68; George P. Smith, "Defective Newborns and Government Intermeddling," (1985) 25 *Med. Sci. L.* 46.

305. *Brahams*, *supra* n. 307 at 13.

306. Id., at 13. See also Mason and McCall-Smith, *supra* n. 307 at 85.

307. Smith, *supra* n. 307 at 46.

308. Brahams, *supra* n. 307 at 13.

309. S.215(1)(a), Criminal Code, R.S.C. 1985, c. C-46, as amended.

310. Id., s.215(1)(b).

311. *R. v. Senior* [1899] 1 Q.B. 283, 68 L.J.Q.B. 175, 19 Cox C.C. 219; *R. v. Brooks* (19L2) 9 B.C.R. 13, 5 C.C.C. 372 (C.A.); *R. v. Lewis* (1903) 6 O.L.R. 132, 7 C.C.C. 261 (C.A.); Dickens, Bernard M. "The Right to Natural Death," (1981) 26 *McGill L.J.* 847 at 870. *R. v. Popen* (1981) 60 C.C.C. (2d) 232 (Ont. C.A.).

312. Lynn, Joanne and Childress, James F., "Must Patients Always Be Given Food and Water?" (1983) 13 *Hastings Cent. Rep*. 17; Lynn, Joanne, ed., *By No Extraordinary Means* (Bloomington, Ind.: Indiana University Press, 1986).

313. This statement is reprinted in *Bio Law A Legal and Ethical Reporter on Medicine, Health Care and Engineering*, vol.1, Resource Manual ss.12-4.1.

314. *Supra* n.277.

315. Id., at 490. See also *Matter of Conroy*, 98 N.J. 321, 486 A (2d) 1209 (N.J. 1985) in which permission was granted to remove a nasogastic feeding tube from an 84 year old bedridden woman with serious and irreversible physical impairments and a limited life expectancy.

316. Sarah Scott, "Are M.D.'s Ever Justified in Killing a Defective Infant with a Lethal Drug?" *Montreal Gazette*, August 9, 1986, A4.

317. *Supra* n.29 at 138.

318. *Supra*, n.138 at 203.

319. Id., at 203.

320. S.215, Criminal Code, R.S.C. 1985, c. C-46, as amended.

321. R. v. Bunting (1926) 58 D.L.R. 373 (C.A.).

322. R. v.Tutton and Tutton (1985) 18 C.C.C. (3d) 328, 44 C.R. (3d) 193, 14 C.R.R. 314 (Ont. C.A.), leave to appeal to S.C.C. granted C.C.C. loc. cit., 60 N.R. 319n.

323. Supra n.29 at 60-61, f.n. 69.

324. Supra, n. 48 at 22. A similar conclusion is reached by Barry B. Swardon and Susan G. Himel, "Legal Opinion on Position Paper: Withholding Treatment", (1979) 24 Can J. Psychiatry, 81.

325. Law Reform Commission of Canada, Some Aspects of Medical Treatment and Criminal Law, Protection of Life Services, Report 28 (Ottawa: Minister of Supply and Services, 1986), p. 8.

326. Smithers v. The Queen (1977) 34 C.C.C. (2d) 427 (S.C.C.).

327. R. v. Kitching and Adams (1976) 32 C.C.C. (2d) 159 (Man. C.A.).

328. Id. at 175.

329. R. v. Torbiak and Gillis (1978) 40 C.C.C. (2d) 193 (Ont. C.A.).

330. Lewis v. The Queen [1979] 2 S.C.R. 821 (S.C.C.); R. v. Yebes (1988) 43 D.L.R. (4th) 425 (S.C.C.).

331. R. v. Vaillancourt (1988) 39 C.C.C. (3d) 118.

332. R. v. Buzzanga and Durocher (1979) 49 C.C.C. (2d) 369 (Ont. C.A.).

333. R. v. Maloney (1983) Time L.R. Dec 22, 1983 (C.A.).

334. Section 219 Criminal Code, R.S.C. 1985, c. C-46, as amended.

335. Section 221 Criminal Code, R.S.C. 1985, c. C-46, as amended.

336. Section 222(5)(b) Criminal Code, R.S.C. 1985, c. C-46, as amended.

337. Id. at 322.

338. R. v. Hnatiuk 91983) 27 Alta. L.R. (2d) 97 (Alta. C.A.); R. v. Clarke (1982) 17 Alta. L.R. (2d) 302 (Alta. C.A.).

339. R. v. Rogers (1968) 65 W.W.R. 193 (B.C.C.A.).

340. R. v. Waite (1986) 28 C.C.C. (3d) 326 (Ont. C.A.).

341. S.238(1) Everyone who causes death, in the act of birth, of any child that has not become a human being, in such a manner that, if the child were a human being, he would be guilty of murder, is guilty of an indictable offence and liable to imprisonment for life.

(2) This section does not apply to a person who, by means that, in good faith he considers necessary to preserve the life of the mother of a child, causes the death of that child.

342. S.223(1) A child becomes a human being within the meaning of this Act when it has completely proceeded, in a living state, from the body of its mother whether or not

(a) it has breathed,

(b) it has an independent circulation, or

(c) the naval string is severed.

(2) A person commits homicide when he causes injury to a child before or during its birth as a result of which the child dies after becoming a human being.

343. Child Welfare Act, S.A. 1980, c.C-8.1, s.s.2, 3.

344. The case was widely discussed. See, for example: Vian Andrews, "Dawson's Case," 41 Advocate 351; Gwen Benjamin, "The Steven Dawson Case: Who Speaks for the Handicapped Child?" (1985) 42 R.F.L. (2d) 167; E.H.-W. Kluge, "In the Matter of Steven Dawson: Right v. Duty of Health Care," (1983) 129 Can Med Assoc J 815; Kathleen Ruff, "The Steven Dawson Case

An Equal Right to Live," (1983) 1 *Just Cause* 17; B. Sneideman, "The Steven Dawson Case: Whose Decision is it Anyway?" (1984) 14 *Man.L.J*. 165.

345. S.B.C. 1980, c.11, ss.1(d), 9, 11(2)(b), (c).

346. Magnet and Kluge, *supra* n.29 at 111-112; Picard, *supra* n.1 at 51.

347. *Re. S.D.* [1983] 3 W.W.R. 597 (B.C. Prov. Ct.).

348. Id., at 610.

349. *Supra* n. 305.

350. *Supra* n. 328 at 615.

351. Id., at 618.

352. Canadian Charter of Rights and Freedoms, Constitution Act, 1982.

353. *Supra* n. 147 at 621.

354. Id., at 629.

355. Id., at 629.

356. Id., at 629.

357. Id., at 633.

358. Id., at 633.

359. Picard, *supra* n. 1 at 51; Magnet and Kluge, *supra* n. 29 at 113. Mackenzie, J. did not find that Stephen was in a persistent vegetative state, while Judge Byrne based her decision on this finding.

360. (1986) 28 D.L.R. (4th) 22 (Que.C.A.).

361. *Supra* n.127.

362. Id. at 170.

363. *See, for example*: *In Re B, supra* n. 304; *Maine Medical Center v. Houle*, *supra* n. 253; *Matter of Storar*, *supra* n. 228.

364. *See, for example*: *In Re B, supra*, n. 304; *Saikewicz*, *supra* n. 212.

365. Supra n.331.

366. (1982) 22 Alta. L.R. (2d) 228 (Alta. Prov. Ct.).

367. Id. at 230.

368. Supra n. 316.

369. Id., at 228.

370. Supra n. 134.

371. Id., at 394.

372. Id., at 396.

373. Id., at 396; but see Judge Byrn's decision in Re S.D., supra n. 335 in which she found a proposed shunt revision to be cruel and unusual punishment pursuant to s.12 of the Charter.

374. However, if the child was old enough to have developed her own religious beliefs, then forcing medical treatment on the child against her will would be a violation of the child's rights under s.15(1) of the Charter. See Re L.D.K.; Children's Aid Society of Metropolitan Toronto v. K. and K. (1985) 48 R.F.L. (2d) 164 (Ont. Fam. Ct.).

375. Id., at 398.

376. Supra n. 106.

377. (1983) C.S. 429. 53 Can. Abr. (2d) 432.

378. [1988] 82 N.R. 1.

379. Id., at 119.

380. Id., at 125.

381. Supra n. 197.

382. Supra n. 358 at 127.

383. Supra n.354 at 171. A blood transfusion given to a 12 year old girl against her wishes was held to be an infringement of her right to security of person.

384. [1985] 2 S.C.R. 486 at 487.

385. Id., at 497.

386. Supra, n. 366 at 129.

387. Id., at 130.

388. Supra n. 372 at 503.

389. Section 212 of the Criminal Code states:

> Culpable homicide is murder
> (a) Where the person who causes the death of a human being
> (i) means to cause his death

390. Law Reform Commission of Canada, Euthanasia, Aiding Suicide and Cessation of Treatment, Protection of Life Series, Working Paper 28 (Ottawa: Minister of Supply and Services, 1980), p.18.

391. See discussion, supra Chapter One.

392. Supra n.378 at 21.

393. Id., at 22. See also Gregory R. Ginex, "A Prosecutor's View on Criminal Liability for Withholding or Withdrawing Medical Care: The Myth and the Reality," in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, edited by A. Edward Doudera and J. Douglas Peters (Ann Arbor, Michigan: AUPHA PRESS, 1982); George A. Oakes, "A Prosecutor's View of Treatment Decisions," in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, edited by A. Edward Doudera and J. Douglas Peters (Ann Arbor, Michigan: AUPHA PRESS, 1982).

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TREATMENT DECISIONS AT THE BEGINNING OF LIFE: LEGAL, MEDICAL AND MORAL ASPECTS

by

PATRICIA LEONE JAMES

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TABLE OF CONTENTS

VOLUME II

Chapter Three: Moral Aspects of Neonatal Decisionmaking 318

I. Two Major Ethical Theories 318

II. Deontological Theories 323

- A. Sanctity of Life Doctrine 323
  - 1. Judeo-Christian Tradition 324
    - (a) Immanuel Jakobovits 324
    - (b) Paul Ramsey 326
  - 2. Secular Tradition 329
    - (a) Richard Sherlock 329
  - 3. The Extraordinary Means Principle as a Limiting Factor in the Sanctity of Life Tradition 333
- B. A Pluralistic Deontological Theory 343

III. Consequentialist Theories 352

- A. Richard McCormick 353
- B. Joseph Fletcher 356
- C. Richard Brandt 359

IV. Personhood Theories 361

- A. Michael Tooley 362
- B. Peter Singer 365

Page

V. Withholding Treatment in the Child's Best Interest 371

  A. Robert Weir 371

  B. Tristram Engelhardt 377

VI. Procedural Approaches 380

VII. The Euthanasia Debate 386

  A. Killing and Allowing to Die - Is There a Difference? 388

  B. The Debate Between Williams and Kamisar . 401

    1. Williams Proposal 401
    2. Kamisar's Rebuttal 403
    3. Critiques of Kamisar's Wedge Argument 404

Chapter Four: Criteria Guiding Decisionmakers . . 423

I. Introduction 423

II. The Factual Basis of Decisionmaking 427

  A. Accurate Diagnosis 428

  B. Prognostic Uncertainty 429

III. Determining the Infant's Best Interests . . . 434

  A. Ethical Guidelines 434

    1. Harms and Benefits in the Neonatal Context 437
    2. Whose View Shall Govern? 442

Page

(a) Best Interests Standard 443
(b) Substituted Judgment Test . . . 444

B. Application of Ethical Guidelines 448

1. Selection by Categories 448
2. Decisionmaking in Borderline Cases . 461

(a) The Distinction Between "Ordinary" and "Extraordinary" Treatment 461
(b) Bayes Theorem 465
(c) Suggested Approach for Difficult Cases 469

Chapter Five: Procedural Issues 477

I. Introduction 477

II. Who Should Decide? 478

A. Parents 480

B. Physicians 485

C. Ethics Committees 489

D. The Courts 491

E. Conclusion 494

III. Reviewing the Decisionmaking Process 496

A. Legislative Review 496

1. The Canadian Experience 496
2. The United States Experience 497

(a) The Baby Doe Case 498
(b) The Federal Government's Response 499

Page

(i) Initial Response 499
(ii) The Revised Rules 503
(iii) The Final Rules 508
(iv) The Child Abuse Amendments 511

(c) Comments Regarding Legislative and Administrative Control Over Selective Nontreatment Decisions 514

B. Judicial Review 521

1. Arguments in Favour of Judicial Review 521
2. Arguments Against Judicial Review . . 525
3. Response to Arguments Against Judicial Review 529

(a) Courts are Too Slow Argument . . 529
(b) Frohock's - Incrementalist versus Final Decisionmaking . 529
(c) Dr. Havard's - Adversarial versus Cooperative Approach . 530

C. Internal Administrative Review 531

D. Hospital Ethics Committees 538

VI. Conclusion 547

Bibliography 569

Newspaper and Periodical Articles 593

Table of Cases 595

Chapter 3: Moral Aspects of Neonatal Decisionmaking

The purpose of this Chapter is to present and evaluate several of the major ethical theories applied by ethicists, theologians and moral philosophers to the moral dilemmas involved in the care of defective infants. Each ethical theory establishes moral standards and rules of conduct which enable a person to know what he ought to or ought not to do in any given situation. [1]

I. Two Major Ethical Theories

There are a number of ethical theories or systems. Kluge describes four basic types: "teleological or goal directed; deontological or rule-focussed; agapistic or love-centered, and religious or belief derived." [2] Of these theories, the teleological or consequentialist, as it is sometimes called and the deontological have dominated western philosophical tradition and continue to be the most widely discussed theories in contemporary moral philosophy. [3]

Teleological theories hold that an action is morally "right" if it, or the rule under which it falls is expected to, or will produce good consequences - "at least as great a balance of good over evil as any available alternative."[4] Teleological theories also specify a standard for evaluating the goodness or badness of the results that flow from a particular action.

The most widely discussed of the teleological theories is utilitarianism which received its classic formulation in the writings of Jeremy Bentham and John Stuart Mill.[5] Utilitarianism can be defined in terms of its basic concept, the principle of utility which may be defined as: "that act is right which all things being equal, produces or is likely to produce the greatest good to the greatest number of people."[6] The standard of value by which utilitarians judge the goodness of the consequences of an act varies. For some utilitarians, such as Bentham it is "pleasure" while for others, like John Stuart Mill it is "happiness". A more recent formulation by G.E. Moore claims that goodness is "a unique and indefinable property of things."[7] These three types of utilitarianism classifed according to these views are known as "hedonistic utilitarianism", "eudaimonistic utilitarianism" and "ideal" or "agathistic utilitarianism."

In order for a utilitarian to determine what he ought to do in any given situation the following procedure is followed. First, all of the possible alternative actions must be specified. Once these possibilities are ascertained, an attempt is made to calculate the probable consequences that would follow from each course of action. Depending on the utilitarian standard of value that is utilized, the question would then become how much 'pleasure', 'happiness' or 'intrinsic good' would result from the act. These consequences are then compared in order to determine which one leads to a greater amount of pleasure (happiness or intrinsic good) and a lesser amount of pain (unhappiness or badness) than any other alternative. From a utilitarian perspective, it may sometimes be morally right to perform an act that will bring about pain or unhappiness. However, this would only happen when that act would bring about less pain or unhappiness than any other.

Utilitarianism can be further categorized as being either act-utilitarianism or rule-utilitarianism. Act-utilitarians take the position that each individual act is to be judged according to its utility while Rule-utilitarians believe "that the act which ought to be done is that which is prescribed by the set of principles which has the highest acceptance utility." [8] Thus, for rule-utilitarians, (utilitarian) rules of conduct are the criteria for judging the moral correctness of an action. For act-utilitarians moral rules may act as a guideline of what generally ought to be done but they do not determine whether acts are right or wrong. [9]

Given a practical ethical problem, proponents of each of these types of utilitarianism could come to a different conclusion.

Deontologists on the other hand, believe that morality may be found in the rightness of the action itself regardless of the end result. Deontological theories hold that there are certain eternal moral principles and obligations such as the duty to tell the truth and the duty to protect life. The central theme of deontological theory is that "the individual is of ultimate and incommensurable value." [10] In this respect, actions are evaluated "by how well [they] preserve the automony of the individuals involved and safeguard ... their respective rights." [11] Any action which infringes or negates such rights is morally wrong even if an apparently desirable result would be achieved.

In the case of an infant with severe defects, a deontologist and rule-utilitarian would be faced with conflicting moral obligations and rules. On the one hand, they may perceive a duty to preserve life but they may also perceive a duty not to cause pain and suffering.[12] An act-utilitarian may in the same situation decide that the morally correct action would be to kill the child as such an action would, all things being considered, bring about less pain than any other alternative. Joseph Fletcher, a leading proponent of situation ethics (a name given to act-utilitarians) argues that situation ethics are better suited to the ethical issues faced by modern medicine. He states:[13]

> Physicians sometimes speak of situation ethics as "clinical" in the sense of looking at each case on its own merits. Through training and practice they are familiar with the importance of diagnosis and prognosis case by case. They know that the 'laws' of medical science do not apply categorically to all patients with a given complaint; they are accustomed to judge what is best not so much by general principles as in their light. Being case-centered, they reject any notion that medicine should be practiced according to moral rules. Guidelines they welcome, yes, but not categorical moral rules.

Fletcher's approach is an appealing one, yet the danger of utilitarianism in practice, given that the end justifies the means, is a diminishment in the value of the rights accorded to the individual in medical practice.

The next section of this paper will examine the application of these theories to the care of defective infants.

II. Deontological Theories

A. The Sanctity of Life Doctrine

The approach most closely associated with traditional deontology has been described as the Sanctity of Life doctrine or ethic. The basis of this approach is the rejection of the claim that one human life is more valuable than another. Every human life is seen as intrinsically good -- the lives of the terminally ill, the severely retarded and the grossly deformed are sacred. The condition of that life does not negate its value or in any way justify its termination. Two main principles flow from this tradition:[14]

1. Since human life is sacred one must not directly or deliberately kill an innocent human being;
2. There is an obligation to sustain human life, wherever possible.

1. Judeo-Christian Tradition

The origins of the sanctity of life doctrine are found in the Judeo-Christian religious tradition. Both Judaism and Christianity believe that life is a gift from God. Being a gift, there are limits to what can be done with it. It cannot be violated or taken away by oneself or others. Human intervention is limited to protecting and enhancing life. The views of two writers, one a Jewish rabbi and the other a Protestant theologian, illustrate the Sanctity of Life doctrine in the Judeo-Christian tradition.

(a) Immanuel Jakobovits

The central premise of Judaism is the Jewish belief and commitment to the sanctity of life. This principle is supported by the underlying premise that attributes "infinite value" to every innocent life. Rabbi Jakobovits explains how the principle forms the basis of Jewish opposition to infanticide and euthanasia: [15]

> Infinity is indivisible. Any fraction of infinity remains equally infinite. Hence, if seventy years of life are of infinite worth, so is one year, one week, one day or one hour of life. All are equally valuable and inviolable.

> And just as the time factor is irrelevant to the worth of life, being infinite, so is the health of a person. Once the principle of infinity is established, it follows that a physically or mentally deficient human has exactly the same value as a completely normal person. 'Half a human being' is no more reduced in value by reason of his incapacity than half of infinity is less than infinity.

The reason behind this principle of infinity is that as soon as human life becomes differentiated in any way - either as to the amount of time left or because of its condition the effect would be that human beings would no longer have an absolute value but would have instead a relative value. No two human beings would be equal in value. Some lives would be superior and others would be inferior. Rabbi Jakobovits argues: [16]

> The whole notion of assessing human life by some arbitrary differential instead of deeming its worth as beyond measure ... is an affront to the cardinal teaching that every human being is created 'in the Divine image'.

Opponents of this tradition argue that in its quest to protect human life regardless of its condition, it ignores the pain and suffering that are part of some lives. The Jewish tradition is not indifferent to such suffering but it is human life and not happiness or wellbeing that outweighs all other values. He notes that

Jewish law has always been concerned with relieving pain and suffering, and cites examples including, modification of Sabbath laws that caused hardship, and duties to refrain from causing avoidable pain to any sentient being, including animals. Nonetheless, he concludes:[17]

> But the one concession Jewish law cannot make is to purchase the relief of suffering at the cost of life itself.

A similar position is adopted by former Princeton theologian, Paul Ramsey.

(b) Paul Ramsey

Ramsey argues that decisions regarding medical treatment should be based solely on medical criteria, which he terms a "medical indications policy". The sole question is whether or not a therapy will relieve the child of a life-threatening or debilitating condition. A distinction is made between the situation where an infant is born dying or suffering from a fatal illness for which there is no known cure and a situation in which an infant is born suffering from a severe congenital disorder or impairment. Treatment may be curtailed in the former case but never in the latter. The physician should not at any time contemplate the question of whether the life of a handicapped infant is so meaningless or onerous as would justify the discontinuation of treatment. Ramsey comments:[18]

> We have no moral right to choose that some live and others die, when the medical indications for treatment are the same ... That means that the standard for letting die must be the same for the normal child as for the defective child.

He cites the example of a mongoloid infant with a bowel obstruction. If an operation to remove a bowel obstruction is normally done to save the life of a normal infant, it is also indicated in order to save the life of a mongoloid infant. Ramsey writes:[19]

> A medical indications policy is the only way to take a middle path between the relentless treatment of the voiceless dying, which refuses to let them die even when disease or injury has won, and killing or hastening death or neglecting to sustain those who are simply voiceless incurables.

Ramsey states that only a physician can identify when an infant is in the "process of dying" or that the infant's condition is "incurable" since these are matters of medical judgment.

He does however, allow for certain exceptions to this policy of sustaining the life of defective infants. The first exception are anencephalic infants since they are not in his view "alive human beings" and are thus unable to be the subjects of rights deserving protection and care.

Ramsey proposes a second exception to the duty to protect and care for human life. In the case of a patient (of any age) who "because of intractable pain or deep coma is totally inaccessible to human care of any sort" [20] then continuing care is in Ramsey's view no longer necessary, since care cannot be conveyed in such cases. He concedes that in these rare cases, positive euthanasia would be morally permissible.

Ramsey's standard for non-treatment - the futility standard, has been criticized for being ambiguous. Richard Sherlock asks, "What counts as futile therapy?" [21] He suggests it is unclear how this standard might be applied in practice. For example, would a 5% chance of success be considered futile or would some other figure be relevant. Similarly, in cases where a treatment can sustain life but not indefinitely, such as total parenteral nutrition for short bowel syndrome, can this be considered futile therapy,[22] or in cases which are terminal for which there is no cure does the doctor treat any other disabling conditions apart from that of the specific disease state? Ramsey would probably say yes, but other complications may, if not treated, lead to an easier death. For example, a patient who is suffering from an advanced cancer and who comes down with pneumonia may have an easier death from the pneumonia than from the cancer itself.[23]

2. Secular Tradition

Richard Sherlock is a theologian who argues that current quality-of-life concepts, such as a "life not worth living" strike at the foundation of the liberal polity upon which our society is based. He presents a secular view of the Sancity of Life doctrine.

(a) Richard Sherlock

Sherlock explains that the political regimes of the modern western world were inspired and derive their existence from the teachings of the founders of modern political philosophy; particularly Hobbes and Locke, and later Rousseau and Kant. These liberal ideals constituted a fundamental change from the notions of classical political philosophy which claimed to know the nature of human excellence or virtue and upheld the natural right of the wise and the virtuous to rule over those who did not meet these standards of excellence.

Modern political philosophers rejected any claims to know the nature of human excellence and distrusted politics based on any claims to such knowledge. Such power in the view of liberal thinkers led to tyranny.

The core premise of liberal theory is the belief in human equality. Sherlock comments "[f]rom this premise everything flows in liberal political philosophy." [24]

This notion of equality is not something that has to be proven; rather, it is assumed as "self-evident" and essentially unprovable. For liberals these rights are possessed by every member of the human species. Underlying the belief in individual rights lies the conviction that human beings have an equal worth or "equality of human dignity." Sherlock quotes a passage from the writings of James Wilson, who was one of the founding fathers of the United States, as well as an associate Justice of the Supreme Court, as illustrative of the liberal concept of equality and individual rights. He wrote: [25]

> When we say that all men are created equal we mean not to apply this equality to their talents, dispositions or their acquirements. In all these respects there is and is fit for the great purposes of society that there should be great inequality among men. In the moral and political as well as in the natural world, diversity forms an important part of beauty; and as of beauty, so of utility likewise. That social happiness, which arises from the friendly intercourse of good offices, could not be enjoyed, unless men were so framed and so disposed as mutually to afford and to stand in need of service and assistance. Hence the necessity, not only of great variety but even of great inequality in the talents of men, bodily as well as mental ... But however great the variety and inequality of men might be with regard to virtue, talent, taste and acquirements, there is still one aspect in which all men ... are equal. With regard to all there is an equality in rights and obligations; there is that jus aequum, that equal law in which the Romans placed true freedom. The natural rights and duties of men belong equally to all. Each forms a part of that great system whose greatest interest and happiness are intended by all the laws of God and nature. These laws prohibit the wisest and most powerful from inflicting misery on the meanest and most ignorant, and from depriving them of their rights or just acquisition. By these laws, rights natural or acquired are confirmed, in the same manner to us all.

There is no place within this tradition for discussing the moral worth of persons based on any characteristics beyond that of membership in the human race. Current discussions among moral philosophers and others which utilize concepts of "meaningful life" or distinctions between "personhood" and "human beings" violate the premise of equal rights for all and the inalienable rights of the individual. Liberal philosophers held that inalienable rights could not be justly alienated by anyone, including the individual. In upholding this principle, Hobbes and Locke wanted to prevent any possibility of a tyrannical regime enslaving its citizens either overtly or covertly. If one could surrender the most basic right the right to life, the possibility existed that one could also alienate other lesser rights, such as liberty. This philosophy is translated into practice by liberal regimes codifying in their laws, these fundamental rights held by all citizens and the granting of equal protection to all. For Sherlock, those who argue that some lives may be ended for whatever reason must be aware that this would not merely entail "a change in some isolated law or policy" rather, "[i]t is to ask that we change the constitutive premises of the regime, those coeval with its existence."[26]

Abandonment of liberal philosophy would result in the breakdown of the organizing principles of our community and jeopardize the future of our society.

Sherlock admits that some infants will die even with skilled medical care. In some cases death may be the result. But he argues that to admit "such sad yet necessary facts" does not in any way justify "wholesale infanticide programs" that would be the logical outcome if society adopted quality of life arguments. [27]

3. The Extraordinary Means Principle as a Limiting Factor in the Sanctity of Life Doctrine

In its most extreme form, the Sanctity of Life principle is expressed: that where there is human life, regardless of its condition or quality, it is wrong to allow life to end. The Law Reform Commission of Canada in a Study Paper on the Sanctity of Life characterized this extreme view of the principle as "vitalism". [28] In practice proponents of this extreme view are rare. Generally, a less rigid interpretation of the principle stops short of valuing life as an absolute. Moderate proponents of the principle agree with its general ideals but allow there can be certain exceptions to general rules of preserving life. The following passage by Warren Reich illustrates this moderate position: [29]

> There is a "deontological" moral duty not to directly and deliberately kill an innocent patient, whether through acts of commission or omission; there is a fundamental prima facie obligation to sustain human life; and the practical limitations of the duty to offer life-supporting efforts are indicated by consequences or qualitative concerns (called "extraordinary" circumstances) in conflict situations.

The ordinary/extraordinary distinction grew out of the Catholic moral tradition. [30] Pope Pius XII in an address to an International Congress of Anesthesiologists used the ordinary/extraordinary means distinction in answer to the anesthesiologists' questions regarding the permissibility of withdrawing artificial respiration equipment in certain situations. Pope Pius, in a widely-quoted passage, explained the duty of the doctor and family: [31]

> But normally one is held to use only ordinary means according to circumstances of persons, places, times and culture - that is to say, means that do not involve any grave burden for oneself or another. A more strict obligation would be too burdensome for most men and would render the

> attainment of the higher, more important good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more serious duty.

Since that time, there have been a number of interpretations of this principle.[32] The definition most commonly cited is that of Gerald Kelly, a Jesuit theologian:[33]

> Ordinary means of preserving life are all medicines, treatments, and operations which offer a reasonable hope of benefit for the patient and which can be obtained and used without excessive expense, pain or other inconvenience Extraordinary means of preserving life mean all medicines, treatments, and operations, which cannot be obtained without excessive expense, pain or inconvenience, or which, if used, would not offer a reasonable hope of benefit.

The principle as stated above focuses on two criteria. The first is that where the treatment itself will cause excessive hardship it need not be used, and second, where there is no reasonable hope of success in medical terms treatment may be withheld.

Leonard Weber, in his book, Who Shall Live? examines both of the above criteria. He looks first at the question of what would constitute no reasonable hope of benefit or success in the case of an infant. For Weber, the fact that we are dealing with an infant rather than an adult will affect our response to this question. He explains: [34]

> Both, because the infant cannot possibly have a say in the matter and because he is just beginning life, we should use a more minimal sense of success or benefit than we might use for ourselves or other adults.

This view is shared by Reich, who writes "it would seem that for a person who has not yet had the opportunity for life and who is totally dependent on others, one should be more than customarily skeptical about what is truly 'extraordinary'." [35]

For Weber, if the medical prognosis is such that with treatment the child will live for more than a year, then the child should be treated provided that the treatment does not cause excessive hardship.

What constitutes excessive hardship for an infant? Treatments that may involve a long, critical battle, even if they would ultimately result in success, can be considered excessively burdensome to a child. In Weber's opinion, "the cost may be too high" where a treatment itself produces a severe handicap, even though it may save a child's life. As an example, he cites a situation where a patient's oxygen supply has been cut off and resuscitation is not possible until it is likely that there has been extensive brain damage. He states that, in such a case, treatment to restore the blood circulation would be extraordinary treatment and hence non-obligatory since at that point it would constitute an excessive burden to the patient. Both Weber and Reich are careful to point out that:[36]

> ... infants are not to be excluded from treatment on the basis of the kind of defect they have, whether physical, mental or relational, but only insofar as the comprehensive treatment causes excessive hardship.

In answer to the question of whether treatment can ever be withheld from an infant on the basis of excessive burden to the family, Weber answers that, as a general rule we cannot tolerate a policy of withholding treatment from someone because he is a burden to others. This however does not mean that we cannot ever consider the infant in a social context as part of a family unit.

Weber suggests that, "it is proper to seek to know what kind of a burden the treatment will place on the family ..." but, he cautions that it would have to be "very intense indeed before it could be considered excessive." 37 The burden would have to be so great that it would threaten to destroy the family unit, and this not be lightly assumed. He again stresses that it is only justifiable not to treat, when it is the "treatment" that causes the burden not the burden that the handicapped child imposes on the family by reason of his condition. Weber suggests that parents who wish to determine whether their decision to withdraw treatment is made on the basis of the child's condition, or on the basis of the type of treatment, should ask themselves whether they would treat the infant if it was going to be "perfectly normal" after the treatment. If the answer is "no", then they can safely say that they are not treating because the treatment itself is too great a burden.

Generally, proponents of the extraordinary means ethic do not view an excessive burden on society as a justification for withholding treatment. Weber states: 38

> I simply cannot understand how treatment that has a reasonable hope of success and does not impose an

> excessive burden on the child or on the family can impose an excessive burden on society.

This view fails to consider the question of whether society is morally obligated to supply extremely expensive treatments to all diseased and handicapped infants. As an American, living under a system of health care where families themselves bear the financial burdens themselves or through private insurers, his view may have more merit than in a country like Canada with a state-financed universal system of health care.

Although the ordinary/extraordinary means distinction has been invoked frequently in the past few years both in medical practice and in judicial decisions, the most notable being the Quinlan case, it has come under increasing attack because of its inherent vagueness and uncertainty in its application. 'Extraordinary' has been variously defined as "heroic", "expensive" or "unnatural" treatment. [39] A number of commentators have suggested replacement terms from Robert Weir's "obligatory/optional, to Robert Veatch's "reasonable/ unreasonable" distinction. [40] In its Working Paper on euthanasia entitled Euthanasia, Aiding Suicide and Cessation of Treatment, the Law Reform Commission of Canada said the distinction is too "imprecise" and "remains too ambiguous to serve as a solid basis for any precise description of the scope of the physician's legal duty to his patient and therefore to serve as a good basis for reform." [41] This view was echoed by the United States President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission discussed the various usages of the distinction and concluded: [42]

> Despite its long history of frequent use, the distinction between ordinary and extraordinary treatments has now become so confused that its continued use in the formulation of public policy is no longer desirable ... Clarity and understanding in this area will be enhanced if laws, judicial opinions, regulations and medical policies speak instead in terms of the proportionate benefit and burdens of treatment as viewed by particular patients.

Other commentators argue that in practice, the ordinary/extraordinary means distinction is indistinguishable from "quality of life" arguments. They suggest that "the crucial variable is something about the patient, not something about the means." [43] Generally the treatment itself is not difficult or burdensome - what is, is the life of the patient, either during or after the treatment. Richard Sherlock criticizes Weber's criteria, stating that the decision is really based on an evaluation of the kind of life the child is expected to lead. He comments:[44]

> Weber's reply to these arguments is to insist that he is referring to those types of situations in which the treatment itself, not the handicap, leaves the child or the family excessively burdened. This distinction is largely spurious. In fact, Weber himself makes this point obvious when he notes that treatment is burdensome to the child if it leaves him or her severely handicapped. In such a case, the reason for refusing the treatment would be the handicap - and hence quality of life - of the child after therapy.

Sherlock continues, saying that the distinction is also "spurious" where there is an "excessive burden on the family". In such cases, the parents are really deciding that a child with a certain kind of handicap is more than they can bear.

Other commentators see the usefulness of the distinction when discussing the subjective view of a competent adult but reject its application in the newborn nursery. Ramsey argues that where the doctrine has been used in special care nurseries it "has led consistently to the starvation deaths of defective children who, had they been normal, would have received life-saving treatment."[45]

In theory, the ordinary/extraordinary means distinction appears to be a useful method of selection for withholding treatment in certain clear-cut cases. In these types of cases, it has an intuitive appeal. Some 'ordinary' treatments are available in large medical centers that would not be available in a small community. Similarly, the decision to cease resuscitating a dying patient on the basis that it merely prolonged the act of dying - and is therefore an extraordinary measure and not obligatory, appeals to common sense. The problem with the distinction is that it can be used in a self-serving manner by parents or physicians. Whatever treatment or care they wish to withhold may be characterized as 'extraordinary'. This view has been demonstrated in practice. Fost points out that in a survey of pediatricians, many consider the repair of a duodenal atresia in a normal child to be "ordinary means" but describe the same operation on a Down's syndrome child as "extraordinary means". He correctly concludes: "The means are the same in both cases, and cannot be ordinary in one and not the other."[46] There is no doubt that both Reich and Weber would argue that repair of duodenal atresias is ordinary and obligatory treatment for normal infants as well as Down's syndrome infants. The problem lies in the application of the distinction in practice.

Without clearly-expressed statements of just what kind of "treatments" would constitute an unacceptable burden, and for what patients, those who invoke the distinction must face the fact that, when practically applied, quality-of-life criteria may be utilized in judging the benefit of certain treatments.[47]

B. A Pluralistic Deontological Theory

Although traditional deontological theories are closely associated with the view that regards all human life as a sacred trust, other deontological theories hold that the right to life is not an 'absolute' right. For these theorists, there are no absolute rights since all rights are subject to limitation by the competing rights of others. Decisionmaking therefore requires a balancing of competing rights.

In their book, Withholding Treatment from Defective Newborn Children, Magnet and Kluge illustrate the application of this theory in the context of decisionmaking within neonatal units. They argue that "[t]he rights of all members must be considered by those who have the task of making decisions."[48] Since infants are incompetent by virtue of their age their rights can only be implemented "if the decisionmakers have the authority to advance and by proxy act on them." [49] The proxy decisionmaker must have complete freedom to exercise the infant's rights, if these rights are to be exercised in a fair and just way. For Magnet and Kluge, "[a]s long as that authority is exercised in strict accordance with the ethical principles governing the balancing of rights, neither the fact nor the use of that power can be attacked." [50] This decisionmaking power cannot be removed from those who have the obligation of decisionmaking unless it is exercised in an unethical fashion, which they define as "ethical malfeasance." [51] Neither the fact that the decisionmaker may be unsophisticated nor completely aware of every alternative amounts to ethical malfeasance; rather, it implies an obligation to seek out and be open to using relevant data in making the decision. A refusal to take this information into account, or to make the decision in an unreasonable manner, would amount to malfeasance.

Magnet and Kluge point out that access to and use of health care services is not obligatory (a duty). It is a right. Consequently they argue, "[i]t is perfectly conceivable that for good and sufficient reasons the proxy decision-makers may decide that the ethically appropriate course of action is not to exercise the right on that occasion."[52]

Since an infant cannot have any wishes or desires as to how his rights can be exercised a subjective approach cannot be used in decisionmaking. The standard is therefore an objective one, that of the 'reasonable person' who may choose whether or not to exercise a certain right and since the neonate exists in both a familial and social situation, the decisionmaker must balance his rights with the rights of all who are concerned, including the parents.

Three important ethical data govern the decision-making: personhood, justice and fairness.[53]

Personhood is central to the question of whether to provide medical care since only 'persons' can have rights, just as only persons can have duties and obligations. Magnet and Kluge suggest that we "assume that the defective neonate is in fact a person and that surrogate decision-making is therefore a propos."[54] An exception to this assumption would be anencephalic infants, who by definition are not persons and who therefore cannot have surrogates. All other defective neonates should be treated as if they were persons even if they do not meet the criteria of personhood.

Justice implies that "all rights must be evaluated with respect to rank and weight vis-a-vis the competing rights of others." [55] Fundamental rights, including the right to life and right to health care would outrank lesser rights that are not as fundamental. Thus, Magnet and Kluge argue that a defective neonate should not denied medical treatment because of financial or parental lifestyle considerations.

Where individuals have conflicting but equal rights, for example, to a scarce medical resource, the principle of possibility allows rights of equal rank to be weighted and thus prioritized. Thus, if the likelihood of success is greater in one case than another, the principle requires that the greater weight be given to the right in the former case.

Medical resources allocated for the treatment of defective newborns become unavailable for the use of others who also have a claim. The use of these resources in neonatal medicine must therefore be justified against the competing claims of others. Magnet and Kluge state: "Rights of equal rank must be weighted not only on the principle of possibility, but also on the basis of equity and justice."[56] Although at first glance it may appear that severely defective infants receive a "disproportionately large share" of medical resources, justice requires that their negative health status be proportionately accounted for in the weighting of rights to medical resources.

The notion of fairness, on the other hand, takes into account the fact that the neonate is in no way responsible for his condition, thus he is entitled to a proportionately large allocation of medical resources.

However, there is a limiting factor in this deontological balancing of rights:[57]

> The allocatory shift must not reach such a degree as to interfere unfairly with the right of access to health care by other members of society. The health status of others may not be lowered below that of the neonate in receipt of the proportionally adjusted allocation.

These principles of resource allocation apply to the individual neonate as well as at the macro-level of neonatal care by introducing an "ethical limit" on resource allocation for a particular infant.

Other ethical principles relevant to the balancing of neonatal rights are cited by Magnet and Kluge. These principles are:

> 1. Principle of Autonomy: All persons have the right to self-determination limited only by unjustified infringement of the rights of others.[58]

Neonates are persons who require their rights to be administered by proxy. The proxy-decisionmaker must not exercise the neonate's right to life and right to health care as though they were duties. A right may be exercised but a duty must be exercised. Respecting the infant's autonomy may mean that the infant has a discretion to refuse his right to medical care in appropriate circumstances. Failure to respect this possibility amounts to a transformation of the infant's right to life into duty to live and violates the infant's autonomy.

> 2. Principle of Priority: Rights can be ranked according to priority.[59]

As mentioned earlier in the discussion, fundamental rights such as the right to life have priority over rights such as financial considerations.

> 3. Principle of Impossibility: A right which cannot be fulfilled under the circumstances is ineffective as a right. An obligation which cannot be met under the circumstances ceases to be an obligation. One is never obliged to demand or do the impossible.[60]

This principle is similar to Ramsey's medical indications policy. When the infant is dying and treatment is futile, the infant's right to life becomes impossible. There is thus no ethical obligation to continue treatment since the right to life can no longer be effectively exercised.

> 4. Principle of Best Action: He who has an obligation, has the ethical duty to discharge it in the best manner possible under the circumstances.[61]

An obligation is determined by the practical exigencies of the situation. What may be the best course of action in one situation may not be in another. The decisionmaker must attempt to do more than good, he must attempt to do the best possible in that particular situation.

> 5. Principle of Relevant Difference: A right is effective to the degree that nothing in the relevant situation contravenes the conditions on which it came into being.[62]

This principle is utilized in order to rank the rights of society and the family. In cases in which the parents had some degree of control over the neonate's condition such as drug use, alcohol consumption or were aware of a genetic condition, their right to increased social assistance should be proportionately reduced based on their degree of responsibility. In practice, this principle would be very difficult to apply, and the further relevant fact of the infant's need which is not self-induced should increase his right to health care.

> 6. Principle of Justice: A right is effective only to the degree that it promotes or preserves justice.[63]

As previously discussed, since defective neonates start life in a negative position in relation to their health, it would be unjust if their rights to health care were the same as those of healthy persons as this would preserve their disadvantage. But the principle of justice requires that any changes made to promote a benefit in the neonate's health should not themselves lead to an injustice.

For Magnet and Kluge, utilizing these ethical principles in the regulation and balancing of the infant's rights by the proxy-decisionmakers means that in some cases the ethically correct decision would be to withhold treatment. In these situations, palliative care does not mean the infant be allowed to die by starvation or dehydration, rather they conclude: [64]

> "An ethically acceptable proceeding requires the administration of medicaments of an appropriate nature and in sufficiently large doses to make for a "fair and easy passage."

Although Magnet and Kluge clearly define the relevant ethical principles which should guide the decisionmaker, it is respectfully submitted that their ethical approach would be useful for policymaking but would provide little concrete guidance for decisionmaking in individual cases. For instance, if, as the authors suggest, the infant's right to life and health care would outrank parental financial and lifestyle considerations, under what circumstances would an infant's right to life result in "an unjustified infringement on the rights of others" (principle of priority versus principle of autonomy)?

III. Consequentialist Theories

A number of different theories regarding the care and treatment of defective infants have been proposed which are consequentialist in nature; that is, they focus on the probable outcomes of treatment as a basis for decisionmaking. These theories generally subscribe to the quality-of-life approach in contrast to the Sanctity of Life views previously discussed.

The central theme of these approaches is the concept of the value of human life and one's moral duty in relation to that value. In the sanctity of life tradition, human life is valued as a 'good' irrespective of its present or future qualities or conditions. There is moral obligation to protect and sustain life whenever possible subject to limited exceptions. In contrast to this view, proponents of the quality of life approach view life as a relative good. Human life is valued on the basis of certain identifiable human qualities.

These ethicists agree that decisions about medical treatment for defective infants should be determined on the basis of projections as to the "kind of life" the infant would have with treatment. The mere fact that these infants can be salvaged is not enough; what is necessary is the potential for attaining a "meaningful life" in view of their physical and/or mental disabilities.[65]

Some quality of life theorists restrict their considerations to the infant's physical and mental disabilities while others take into consideration the environment in which the newborn will live. Other theorists include the current and future interests of parents, siblings and society as factors to be calculated in decisionmaking.

A. Richard McCormick

Richard McCormick, a Roman Catholic theologian, in a classic article discusses the question of "when, if ever, is it possible to let infants die".[66] He examines the "extraordinary" means distinction and concludes that "it has been so relativized to the condition of the patient that it is this condition that is decisive." [67] Thus, the determining factor in treatment decisions is the quality of the infant's life.

McCormick examines the Judeo-Christian tradition and explains that, in that tradition while life is a good it is only a good that is to be preserved as a condition of the attainment of other higher values. The duty to preserve physical life, as well as the limits of that duty, are based upon the possibility of attaining these higher values. For McCormick, physical life is subordinate to the attainment of spiritual goods - the love of God and of neighbour. This love is inseparable as it is through love of others that man expresses his love of God. The meaning and purpose of human life are thus found within human relationships. He concludes that "life is a value to be preserved only insofar as it contains some potentiality for human relationships." [68] If that potential does not exist or would be totally subordinate to the struggle for survival, then treatment is not obligatory and the infant may be allowed to die.

The application of this guideline to defective newborn infants is left up to doctors since they must determine the biological indicators or symptoms by which an infant's relational potential may be judged. He comments that it is generally agreed that anencephalic infants lack relational potential, but the same cannot be said of mongoloid infants. The task ahead for doctors will be to develop criteria for judging cases which fall within a grey area between these two conditions.

There undoubtedly will be mistakes made and some infants will die because it is mistakenly assumed that they lack any relational potential. It is for this reason that McCormick cautions that we should try to err "on the side of life".

Finally, he concludes that although his proposal will allow some infants to die based on considerations as to their quality of life, this does not mean that some lives are valuable and others are not. Every person is of incalculable worth - he is a value. But the issue, McCormick argues, "is whether this undoubted value has any potential at all, in continuing physical survival, for attaining a share, even if reduced, in the 'higher more important good'." [69] Thus, the question is whether the infant's life offers any possibility of achieving those values for which physical life is the fundamental condition.

A number of criticisms have been raised against McCormick's position.[70] The first pertains to his use of "relational potential" as a criterion. It is said to be "vague" and "uncertain" offering no real guidance to a decisionmaker. Furthermore, it is impossible to measure newborn infants' capacity for relational potential and even if it were possible to measure with some degree of accuracy, what "degree" of incapacity would mean that life is not worth preserving. Other commentators have suggested that McCormick has misinterpreted the basic teachings of the Judeo-Christian tradition which has never based the duty to protect human life on the possession of specific qualities. It has instead based a duty to care and sustain human life due to its intrinsic value and "because of God's relationship to it."[71]

B. Joseph Fletcher

Joseph Fletcher agrees with Richard McCormick that quality of life judgments must be made in neonatal cases. His criteria differ from McCormick's, however, as does his approach. While McCormick bases his views on theological considerations, a "religious" consequentialism, Fletcher's views are based on a "modified act agapism" which he explains, "simply means that loving concern for human beings comes first, before rules of conduct." 72 The approach that Fletcher takes is to do what offers the greatest benefit or good in each and every situation. In some instances this would require saving lives while in others it would mean ending them by active or passive euthanasia. Fletcher's primary value is human well-being which is obtained by maximizing happiness or minimizing suffering. In his view, "it is better to be dead than to suffer too much or to endure too many critical deficits of human function." 73

He originally proposed certain indicators of "humanhood", including 15 "positive" human criteria and 5 "negative" criteria. These ranged from "minimal intelligence", "communication", "concern for others" to "curiosity" and "ideosyncrasy". 74 In a subsequent article, he restricted the criteria to four essential features of persons. These were neocortical function, self-consciousness, relational ability and happiness. The most important of these traits was neocortical function, which he described as "the key to humaness, the essential trait, the human sine qua non ..." 75 Moreover, unlike the other criteria Fletcher proposed, neocortical function could actually be measured. In his view, any individual whose score was below 40 on an IQ test, was "questionably a person"; a score below 20 meant they were "not a person".[76]

Fletcher's criteria enables a line to be drawn separating "persons" from "non-persons". He argues, there is nothing morally wrong with terminating non-persons and he includes Down's syndrome infants in this category.

For those infants who meet his criteria of personhood there is still the ethical question of whether, in some situations, the life of a defective infant (who is also a person) can be ethically terminated. The central issue for Fletcher is not the "quality of personhood", it is "whether the foreseeable consequences of the child's life will be too onerous for all those who will be affected by the child's defects."[77] To answer this question, Fletcher applies his utilitarian calculus based on the principle of "proportionate good" in order to determine whether the infant's life should be sustained or terminated. He includes both financial and emotional considerations in his calculus. Once these factors are weighed and assessed, a decision can be made.

Fletcher sees no moral difference between actively killing an infant or withholding treatment so that it will die, though he does believe in some instances "direct termination" would be preferable as it would minimize the suffering of all the parties concerned.

Critics of Fletcher's theory focus on his questionable, highly speculative and dangerous criteria for evaluating human life. The weak under Fletcher's system would have no protection; they would always be vulnerable when balanced with their effects on the quality of the lives of others.[78] Others argue that while intellect and rationality are basic values, they are not the criteria of being human.[79] Finally, any calculations as to the future worth or good of a child's life are subject to arbitrary decision. In sum, Fletcher's theory fails to meet basic standards of justice and fairness - since it is based upon social discrimination and the idea that some are worthy of less respect than others.

C. Richard Brandt

Arguing from the perspective of a eudaimonistic utilitarian, Richard Brandt asserts that we know that the prospective life of some defective newborns is bad. The standard he uses to judge whether a particular life is bad is a "happiness" criterion. He divides life into moments of experience and states: [80]

> If a person likes a moment of experience while he is having it, his life is so far good; if a person dislikes a moment of experience while he is having it, his life is so far bad.

Using these moments of experience, Brandt suggests that we can establish a "happiness curve" for a defective infant. The centre of the curve would be an "indifference axis." When a moment of experience is liked it would be above the indifference axis; if it was disliked it would be below. He explains, "this criteria would say that a life is worth living if there is a net balance of positive area under the curve over a lifetime, and that it is bad if there is a net balance of negative area." [81]

Brandt argues that we know that the prospective life of a defective newborn is less good than that of a normal infant. The question then becomes, is such a life bad. In his view, on the whole, the lives of such children when gauged according to the happiness criterion are bad. He reaches this conclusion by comparing a defective child's potential happy experiences with his unhappy ones. On the negative side, Brandt suggests that the child's life would be boring or uncomfortable although he does see some positive enjoyments such as "eating, drinking, elimination and seeing the nurse come with food.".[82] But, he does not believe that these "brief enjoyments" outbalance the "long stretches of boredom, discomfort or even pain" that the child would face. Brandt thus concludes that the overall quality of these infants' lives would "be bad on the whole" and argues that we would be doing them a favor by terminating them.

The problem with Brandt's theory is that he gives no guidance as to where we are to place any given moment on the curve.[83] Furthermore, his criteria are capricious and arbitrary. We have no way of knowing whether such infants would find their lives boring, or that they would not have pleasures other than the ones Brandt himself has imagined. His theory is so ambiguous that it would be impossible to apply it on a practical level since it could apply to anyone who is unhappy for any reason.

IV. Personhood Theories

In contrast to the sanctity of life ethic and quality of life views which are concerned with the value of the infant's life, personhood theories determine the moral obligation to a defective infant based on the status of the infant as a person or a non-person.

These theorists distinguish between "human" which is a biological concept meaning, a member of the species homo sapiens and "person" as a moral status. [84] They argue membership in the species homo sapiens is irrelevant to an individual's status as a person. Although there are some differences in their views regarding which properties or characteristics are sufficient for "personhood", these philosophers submit that unless a being meets the requirements of personhood, it has no right to life and thus its life may be justifiably terminated.

A. Michael Tooley

Tooley, in an article discussing the morality of abortion and infanticide, argues that the basic issue is that of personhood, for only persons have a "serious right to life." [85]

Tooley initially considers what it means to have rights. He sees rights as being conditional. To have a right to something means that the individual is capable of desiring the thing and having this desire means that others have a "prima facie obligation" not to deprive him ~~of~~ it so long as he desires it. He cites an example, "If you do not care whether I take your car, then I generally do not violate your right by doing so." [86]

Tooley then considers the question of what constitutes the right to life. He states: [87]

> ... my argument has been that having a right to life presupposes that one is capable of desiring to continue to exist as a subject of experiences and mental states. This in turn presupposes both that one has the concept of such a continuing entity and that one believes that one is oneself such an entity. So an entity that lacks such a consciousness of itself as a continuing subject of mental states does not have a right to life.

A normal adult is capable of conceiving of himself as a continuing subject of experiences and can desire that he continue to be so in the future. Fetuses and infants however are incapable of having such a desire, consequently they are non-persons and the termination of their lives is morally acceptable at least for a short time after their birth.

Tooley rejects any argument that a right to life can be based on potential. In other words, a normal newborn infant's potential attainment of personhood cannot distinguish it from the severely defective newborn who has no such potential.

He illustrates the "falsity" of the potentiality principle by the following analogy: [88]

1. He suggests that if a chemical was discovered that when injected into the brain of a kitten would cause that kitten to have all the psychological capabilities of a normal adult, it would be morally wrong to ascribe a right to life to human adults but not this kitten.
2. It would not be seriously wrong to choose not to inject the kitten with this chemical but to kill it instead.
3. He argues that if it is not wrong to fail to initiate the process then it is not seriously wrong to interfere with the process providing the kitten had not yet developed the properties that would endow it with a right to life.

He submits that if it is not seriously wrong to kill an injected kitten who will potentially have the qualities necessary for a right to life, neither is it seriously wrong to kill an infant prior to his acquiring these same qualities.

Tooley concludes that it is not necessary to know exactly when a newborn infant acquires a right to life although he cites neurophysiological and bioelectrical evidence in support of behavioral evidence that these mental capacities emerge much later than the newborn period. Infants, in his view, "become quasi-persons at some time after birth, perhaps as early as three months of age."[89] Around this time, he concludes,[90]

> ... they probably acquire properties that are morally significant, and that make it to some extent intrinsically wrong to destroy them. As they develop further, their destruction becomes more and more seriously wrong, until eventually it is comparable in seriousness to the destruction of a normal adult human being.

He suggests that in most cases where infanticide is desirable, it will be known shortly after birth. Therefore, he suggests that a week after birth be set as the interval during which infanticide would be permitted.

B. Peter Singer

Singer argues that the concept of human is used in two senses. In the first sense it has regard to "human attributes" while in the second sense, it refers to members of the species, homo sapiens. These "human attributes", Singer argues, are "relevant to the moral significance of taking life." [91] Species membership alone is not morally relevant since some infants who are human in the biological sense do not and will never possess any of the morally significant human attributes. On the other hand, there are many animals who do possess these characteristics, including chimpanzees, pigs, cows and chickens. [92]

Singer claims that those who hold the Sanctity of Life principle understand the meaning of human in the strictly biological sense. They include all members of the human species but no members of any other species. He states that the principle is "speciest" in that it discriminates against non-human beings despite their having "capacities equal or superior to those of a member of our own species." [93] Singer rejects the Sanctity of Life doctrine and holds that human life per se should not be valued higher than that of non-humans.

The attributes that give life value in Singer's view are rationality, self-consciousness and a capacity to envision a future. Consciousness is important since there are certain things that ought not to be done to a conscious being. We should not cause it to suffer without good reason. But mere consciousness is not enough. Thus, killing a sparrow would not be equated with the killing of a normal, adult human being. In Singer's view, [94]

> ... it is much worse to kill a being with self-awareness and a sense of the future than to kill a being utterly incapable of entertaining any hopes or desires about what might or might not happen to it in the future.

Singer agrees with Tooley that the underlying principle on which the wrongness of an action is based is "related to the extent to which the action prevents some interests, desires or preferences from being fulfilled." [95] Since infants have no desires related to their future there is nothing intrinsically wrong with killing defective or normal infants.

Singer however, diverges from Tooley's position regarding the weight given to a newborn infant's potential. He believes that there may be good reasons to protect the lives of newborn infants even though they don't have the right to life. He cites four reasons which would limit the cases in which killing a newborn would be defensible: [96]

1. The greater the infant's potential for a worthwhile and happy life, the less justification there is for killing it.

2. Most babies are wanted and loved by their parents. Killing such an infant would inflict a terrible wrong on those parents, regardless of the infant's right to life.

3. Even if the parents rejected the infant, someone else may wish to adopt it or care for it. Again, killing the baby would be inflicting a harm on that person or persons, apart from the infant's rights.

4. The fact that an infant does not have a right to life does not mean that it possesses no other rights. As long as they are alive, they may have some rights. Newborns can feel pain, cold and hunger. They can desire not to experience any of these states. Singer argues that it is "plausible to suppose that newborn infants have rights to have their pain relieved, and to be kept warm and fed." Though these rights are not absolute, they show what we should not do to infants without overriding reasons.

Given the fact that normal infants will more likely be able to satisfy one of Singer's enumerated reasons, as well as the fact that they have a much greater potential to become persons, it is easier for Singer to justify killing or withholding treatment from defective infants.

A

Singer further justifies this view by arguing that if a defective infant is killed it may be replaced by a normal, healthy child. He cites studies which show that parents who have a defective child are less likely to have further children compared to other families. Singer argues that we already accede to this by allowing women to abort defective fetuses. Neither the fetus nor the newborn infant are "persons" therefore there is no moral difference in terminating one or the other. His conclusion based upon a utilitarian rationale would allow for the termination of a defective infant for this reason: 97

> When the death of a defective infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the defective infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second.

Singer suggests an arbitrary line be drawn at 28 days after which the infant could not be terminated. This he believes is long enough to confirm the presence of most major birth defects given the current state of medical science and technology.

The most serious criticism that can be made against Tooley's and Singer's personhood theories is that they (particularly Tooley's) would allow "unlimited, indiscriminate termination of an indeterminate number of neonatal lives."[98] Any unwanted infant could be killed for whatever reason since they are not persons.

Since personhood status is something that one either has or does not have, both theorists are forced to set arbitrary times at which an infant will be deemed to have achieved personhood (one week after birth for Tooley and 28 days after birth for Singer). Yet neither of these time periods comes close to corresponding with the time when an individual would develop the requisite capacities Tooley and Singer argue are necessary to being a person.[99]

Robert Weir has argued that Tooley's rejection of the potentiality principle is counter-intuitive since we generally attribute some value to individuals based on their future potential.[100]

Another criticism of Tooley's and Singer's theories focuses on their concept of rights. Both ascribe rights to infants not to be caused unnecessary pain, though they have no rights to life. Warren Reich and

David Ost point out that, based on these principles it would be a greater wrong to draw a non-therapeutic blood sample from an infant than to take its life. They conclude: [101]

> There is something counter-intuitive about a theory which requires a serious justifying reason for subjecting an infant to the prick of a hypodermic, yet permits us to take the infant's life on less serious grounds.

Finally, these theories differentiate between "persons" and "non-persons" on the basis of one right - a serious right to life. They fail however to provide any guidance as to the adjudication between animal rights and human personal rights if they conflict. [102]

V. Withholding Treatment in the Child's Best Interest

A. Robert Weir

Robert Weir, in his book, Selective Non-Treatment of Handicapped Newborns, proposes the child's best interests as a standard for non-treatment of defective infants. It focuses on the child's interests rather than the interests of other parties. As a guideline it emphasizes the burden of continued existence rather than the projected quality of life. Ethicists who advocate this standard argue that non-treatment is only justifiable when death appears to be in a non-dying infant's best interests and Weir believes that there would be fewer infants selected for non-treatment utilizing this approach than with either the quality of life approaches or personhood theories.

Weir explains the difference between the best interest standard and quality of life theories as follows: 103

> The central question in the quality-of-life position can be phrased in this manner: does a handicapped infant (mentally deficient, paralyzed, blind or whatever) have the likelihood of a meaningful life? In contrast, the central question in the best interests position is this one: given the possibility that a handicapped infant will not have a meaningful life by normal (non-handicapped) standards, is that life likely to represent a fate worse than death or a life worth experiencing even with the handicaps?

The method by which the infant's proxy can determine the infant's best interests, according to Weir, is through a combination of the principles of beneficence and nonmaleficence. The principle of beneficence requires the moral agent to confer positive benefits while the principle of nonmaleficence (primum non nocere) requires that the moral agent refrain from doing harm. These two principles in addition to the principle of justice provide the ethical basis of neonatal decisionmaking.

Weir submits that in most neonatal cases the operative principle will be the principle of beneficence since in the majority of cases, continued living is in the infant's best interest. However, he contends, there are a few cases that would lead one to conclude that continued living would represent a "fate worse than death." [104]

In these cases, the proxy must consider whether death when compared with "ineffective treatment and injurious life" is a lesser harm and therefore in the infant's best interest. Weir contends that in some of these cases, withholding treatment is less harmful to the infant than is treatment to extend the child's life. This is because even with treatment little can be done for these infants. Their life expectancies remain very short and many will suffer from severe neurological deficiencies along with a host of other physical and medical problems, ranging from seizures and convulsions to paralysis and blindness. In Weir's opinion, the principle of nonmaleficence imposes a "duty not to treat" infants in such cases.

In addition, the principle of justice requires that similar cases be treated in a similar manner. 105 Applying this principle in neonatal care requires that infants with the same conditions (diagnostic categories) be treated similarly. Utilizing this approach will avoid unfair quality of life assessments that are made by comparing defective infants with normal infants, since these diagnostic categories can be objectively determined by medical consensus. 106

In most of these cases, selective non-treatment will result in the infant's death. But Weir recognizes that in some instances untreated infants do not die quickly or easily. He therefore advocates the intentional killing of infants who, after treatment is withheld, lapse into prolonged and painful suffering; suggesting as a possible method, an injection of intravenous potassium. He writes, "the intentional killing of birth-defective newborns is necessary in rare circumstances as a moral option of last resort in neonatal medicine" and "is justifiable under three necessary and jointly sufficient conditions."[107] These conditions are firstly, that treatment has been judged not to be in the child's best interests; secondly, that without treatment the child will undergo prolonged suffering, and lastly, that death be induced in a quick and painless manner.

The best-interest test proposed by Weir appears to be a better ethical option than the quality of life theories or the personhood theories discussed earlier, since it focuses primarily on the medical condition of the infant. However, he limits his arguments to a specific group of cases involving defective newborns, yet, if life is a "fate worse than death" for these infants, it must similarly be the case for older children and adolescents who suffer from these afflictions. Treatment would be equally wrong for someone of any age who would be injured by continuing existence.[108]

Another criticism can be made regarding Weir's conception of the issue of killing. In focusing solely on the interest of the infant, he ignores the effect that this would have on the persons doing the killing and on society as a whole. Thomas Murray, a medical ethicist from the University of Texas, argues that there may be great moral costs implementing his proposals both to society and to the "human agents" who are doing the killings. He argues that in taking an innocent life: [109]

> Can any one of us perform an act that we have been led to believe is perhaps the most profoundly wrong thing that we can do, without suffering some consequences, without feeling that we have done something gravely wrong?

Similarly, although society does justify the taking of life in some instances, as in war or in repelling an unprovoked attack, these cases involve killing persons who are "unjust aggressors" or "have surrendered their innocence". Seriously ill infants cannot be classified in either category. Murray contends that a society which purports to support and uphold innocent life "mire[s] itself in a dangerous contradiction when it condones the taking of innocent life." [110]

Finally, often it will not be clear whether treatment is in the child's best interests or not. In these cases, Weir's concept of the "harm" principle does not provide much assistance to the decisionmaker because the answer may be unknowable for some time to come.

B. Tristram Engelhardt

Engelhardt submits that infants and young children are not "persons" in the same way that adults are. However, he rejects Tooley's restrictive concept of personhood. He suggests that infants may be "persons" in a social sense. They are highly valued because they have the potential to grow up to be persons and because they assume a social role in human relationships. As a result, rights are imputed to infants, obligations are assumed towards them, and they are treated as if they are persons.

Thus, although infants do not have a right to life in the same sense as actual persons, because of their high value and social status, there must be morally good reasons to justify withholding treatment. Engelhardt contends that a major factor in the decision to treat or not treat should and often will turn on the probability of the infant's achieving a "developed personal life".[111]

Parents, Engelhardt believes, are the proper decisionmakers and are entitled to take into account quality of life considerations in making treatment decisions. Thus, where the infant is likely to have a poor quality of life and treatment is very costly, there is no positive duty to treat. However society has a duty to intervene in cases where parents refuse treatment when the child can attain a good quality of life and the treatment does not constitute a severe burden to the parents.

After proposing what is essentially a quality of life position, Engelhardt presents an alternative proposition. He suggests that decisions should be based on the viewpoint "of the child or even the person that the child might become." [112] From the perspective of the infant, there can be an obligation "not to treat" in some circumstances.

Claims that life can be an injury have been recognized by law in tort actions for "wrongful life." The tort of wrongful life implies "that there is a duty not to prolong life which has a real negative value for the person involved." [113] Engelhardt explains that this concept could be applied to the situation of many severely defective infants for whom treatment can only extend their misery. In these cases, he suggests that what is needed is a new ethical category, the concept of "injury of continuance of existence" which he proposes as a moral analogue to the legal concept of tort for wrongful life.

The tort has been recognized in the United States but has been rejected by Canadian and English courts. [114] This concept would recognize that in some cases the medical maxim primum non nocere (the harm principle) would not require that life be sustained. Where treatment would prolong further suffering, "a decision for active euthanasia would be permissible, even obligatory." [115] However, he adds a proviso that one's duty to hasten the death of a particular child could be overidden by "one's duty to protect children in general." [116]

Critics of Engelhardt's theory have argued that it involves an arbitrary determination as to when life would be such a burden that death would be preferable, since Engelhardt fails to identify either the kind or degree of "harm" that would justify the decision to withhold treatment, or to specify the circumstances in which this duty would be transformed into a duty to actively kill the infant.

Finally, the best-interests test proposed by Engelhardt and Weir requires a comparison of a severely handicapped existence with non-existence for another person.

Certain commentators, such as Paul Ramsey believe that this forces us to make an impossible comparison. He argues: [117]

> ...[s]ince all our everyday evaluations take place against the backdrop of the assumed value of life, we cannot make the comparison of life against non-life demanded by the best interests standard without floundering on conceptual incoherence.

VI. Procedural Approaches

There are two major issues relating to the treatment of defective infants; one substantive and the other procedural. In the ethical approaches discussed thus far, each of the commentators has endeavored to answer the substantive question of whether it is ever morally permissible to allow defective newborns to die. These writers have also attempted to provide criteria for distinguishing those infants who should be saved from those who should not. The foregoing discussions show that there is intense disagreement among ethicists regarding the proper criteria for making the decisions and in the actions that may be taken in light of these decisions. These wide-ranging views reflect the lack of societal consensus in this morally complex and troubling area.

In view of the wide-spread disagreement in this area, some writers have suggested that the procedural question of who is to decide is of fundamental importance. A number of ethicists and physicians have called for "unfettered parental discretion" in making treatment decisions for their children, while others have argued that the decisionmaking process should be characterized by objective, impartial decisionmaking. Norman Fost, who supports the latter approach explains that it is based upon "ideal observer theory" which holds that an action is morally right if it would be approved by an ideal observer who possesses the following qualities: 118

1. omniscience, meaning access to all the relevant available facts;
2. omnipercipience, meaning an ability to imagine vividly the feelings of others involved;
3. disinterest, meaning having no vested interest in the outcome;
4. dispassion, meaning not being overwhelmed by feelings so strong as to cloud critical thinking; and
5. consistency, meaning similar cases could be decided similarly.

Since one individual is unlikely to possess all of these "God-like qualities", Fost suggests that "a process might better emulate the ideal observer than would an individual";[119] citing the use of hospital ethics committees as an example. He concludes:[120]

> A decision resulting from a process that embodied these concepts would not necessarily be right, but it would be more likely to be approved by an ideal decisionmaker.

Philosopher, Terrence Ackerman, on the other hand, maintains that parents should be able to exercise their discretion in making decisions concerning the life or death of their child. In an article proposing a treatment policy for children born with spina bifida, he discusses the extensive burdens -- emotional, psychological, social and financial that raising a spina bifida child imposes on a family.[121] Ackerman believes that whatever the definition of a meaningful life for the child is, the child can only achieve it, given the parents' commitment to adequately care for and nurture that child. If they do not believe that the child can have a meaningful life, they will unlikely provide the kind of care that will make it meaningful. Therefore, he concludes that the parents, after consulting with medical experts should be allowed to decide whether or not the child should be treated.

Goldstein, Solnik and Freud, in their book, Before the Best Interests of the Child also favor broad parental discretion in making treatment decisions for their children. They submit that parents should have the discretion to withhold life-saving treatment from their child if the child is unlikely to "have either a life worth living or a life of relatively normal growth."[122] The authors contend that where reasonable people disagree about whether a life is worth living the choice should be left up to the parents. Thus a child would be permitted to die if: (1) the parents wanted the child to die, and (2) reasonable people disagreed about whether the child's life was worth living.

John Arras argues that this approach is based upon what Rawls has called "pure procedural justice" which is defined as:[123]

> ... in the absence of any independent criterion for what would count as a just result, we can establish procedural rules that can be agreed upon as being fair, and we can accept as fair whatever results happen to be generated by our procedure.

Arras points out however, that Rawls chose to demonstrate his theory of procedural justice by illustrating its application in a non-moral sphere:

gambling. Rawls cites an example of a world poker series where one player eventually ends up with all of the chips and argues that, as long as everyone has agreed prior to the game to play by the same rules, all will agree that this result is fair.

In Arras' view, this theory would rarely apply "in the domain of morality" and he contends that it cannot be "seriously maintained that the issue of impaired newborns is a problem of pure procedural justice." 124 This view is echoed by Richard Sherlock, who writes: 125

> Unless we are willing to adopt the unreasonable proposition that parents should have this choice for death respected in every case - ... then we still need to find an acceptable answer to the question of just when life does become not worth living ... Any scheme which permits discretionary judgment in any context requires for its cogency some clear notion of precisely when the decisionmaker is permitted to exercise his or her discretion. Sometimes we might permit the exercise of discretion in all instances. But this cannot be the case here; otherwise, we would evaporate the category of medical neglect. The question cannot simply be avoided simply by relying on the decision of parents, physicians, hospital committees and courts. The argument made about parental choice applies similarly to all proposed third parties who might render a decision that a given infant ought to die rather than live with one's handicap.

Both Fost's ideal observer theory and Ackerman's absolute reliance on parental choice are deficient in that they allow the decisionmaker to utilize whatever standard he wishes.

Not all parents have their child's best interests at heart when making decisions regarding their children's welfare. Parents make decisions for both good and bad reasons. If Ackerman's approach were implemented there is no reason why parents who gave birth to a normal but unwanted infant could not argue that they were unable to offer the care and nurturing necessary for the child to achieve a meaningful life. Although proponents of this view might argue that this discretion is only meant to apply in situations where the child suffers some deficit or handicap it is still necessary to know what degree of handicap is necessary to trigger total parental discretion in decisionmaking.

Goldstein and his associates fail to define "reasonable people" nor do they give any indication of what attributes or conditions make life not worth living. Is it enough that one reasonable person thinks that a child's life is not worth living in order to permit an infant to die? What if the parents disagree? Goldstein's approach, in addition to being ambiguous could also lead to unwanted infants being denied life-saving medical treatment for spurious reasons.

A similar criticism can be made in regard to Fost's ideal observer theory, for although it limits the decisionmaker's discretion somewhat by requiring similar cases be decided similarly, it fails to provide any substantive criteria necessary to "draw the boundaries of legitimate discretion." [126]

VII The Euthanasia Debate

"Euthanasia" is derived from the Greek and means "good death", although the term is used in different contexts to describe different acts. [127]

First, euthanasia may be voluntary or involuntary. Voluntary euthanasia refers to instances where the victim requests or consents to his own death, while involuntary euthanasia occurs where the victim does not consent or is unable to express any opinion whatsoever. Examples of the latter group include unconscious patients as well as infants.

Euthanasia may also be characterized as active or passive. Active euthanasia involves doing something (an act), such as killing a patient for reasons of compassion, while passive euthanasia usually involves refraining from doing something (an omission) which could save or otherwise prolong a person's life. While active euthanasia is clearly illegal, passive euthanasia is generally not, unless there is a duty to act, i.e., failure to provide the necessaries of life as stipulated by s.215 of the Criminal Code. Law is based upon the assumption that there is a distinction between killing and letting die. However, a number of philosophers have questioned whether this distinction has any "moral relevance".

The ethicists whose views have been discussed in the preceding section of this paper, illustrate the differing views that philosophers hold with respect to this issue. The first view, which may be described as the extreme sanctity of life approach is exemplified by the writings of Richard Sherlock who believes that the life of every infant should be saved if medically possible and would prohibit both active and passive euthanasia. Those who hold the second view, such as Richard McCormick, do not believe that all infants' lives must be saved. They would allow certain infants to die by withholding or withdrawing treatment but would not permit a physician (or anyone else) to actively kill an infant. Ethicists who support the third position, such as Eike-Henner Kluge, Peter Singer and Michael Tooley, would permit treatment to be withheld or the baby's life to be terminated in certain cases. These ethicists argue that there is no morally significant distinction between killing and letting die (for the purpose of euthanasia) and that the law should be changed to reflect this.

A. Killing and Allowing to Die - Is There a Difference?

Philosopher, James Rachels argues that the traditional doctrine which holds that there is an important moral distinction between active and passive euthanasia whereby the latter is generally permissible while the former is always forbidden may be challenged on several grounds. [128] He cites four arguments against the use of the distinction. His first argument is a basic utilitarian argument - allowing a patient to die can result in a long and drawn out, agonizingly painful death while on the other hand, death by lethal injection is generally quick and painless.

Secondly, he argues that the use of the active/passive euthanasia distinction results in life and death decisions being made on irrelevant grounds and should therefore be rejected.

As an example, he cites the case of a Down's Syndrome infant with an intestinal blockage who requires surgery to survive. Often a decision is made not to operate, and the baby then dies. If there had been no blockage the baby would have continued to live. Rachels argues, if the baby's life is worth preserving it shouldn't matter that it needs a simple operation. On the other hand, if a Down's Syndrome infant's life is not worth preserving, then it shouldn't matter that it has an unobstructed digestive tract. In either case, he suggests that it is the Down's Syndrome and not the baby's intestines which is the relevant issue.

The idea that there is an apparent distinction between active and passive euthanasia leads to this result, he argues, for when "there is an intestinal blockage, one can 'let the baby die', but when there is no such defect there is nothing that can be done, for one must not 'kill' it". 129 In his view, this constitutes an irrelevant argument for life or death decisions, therefore the distinction should be rejected.

His third argument is based upon the premise that there is no morally significant difference between killing and letting die. To illustrate his thesis, Rachels constructs two identical fact situations except that one involves a killing and the other allows letting someone die. In the first fact situation, Smith who will be a beneficiary upon his cousin's death, sneaks into the bathroom, drowns the child and arranges it to look like an accident. In the second example, Jones also stands to benefit upon his nephew's death. He attends the bathroom intending to kill his nephew, but is pleasantly surprised to find his nephew is drowning. He waits to make sure and to assist, if necessary. It isn't necessary as the child dies without his assistance. Rachels contends that both Smith and Jones intended their respective nephews to die and they are both equally culpable in a moral sense. From this example, he contends that there is no morally significant difference between killing and letting die.

Applying this analogy to a medical situation, Rachels concludes that letting a patient die or administering a lethal injection for compassionate reasons are morally equivaleht, "For" he asks: "What is the cessation of treatment, in these circumstances, if it is not 'the intentional termination of life of one human being by another?'" [130]

Rachels' final argument against the active/passive euthanasia distinction is a refutation of the view that in passive euthanasia a doctor does not cause a patient's death since he does nothing but let the patient die. This view is based upon the notion that since no physical activity is involved there is no act, and moral culpability applies only to acts not omissions.

Rachels responds by pointing out that in such a case the doctor does perform an act: "He lets the patient die" which he argues "is a kind of action that one may perform by way of not performing other actions." [131] Thus, he concludes that the argument for a distinction between active and passive euthanasia based upon causation is invalid. This view is shared by Magnet and Kluge, who argue that the error occurs by incorrectly "identifying lack of causal determinancy with absence of action." [132] They explain: [133]

> What is ethically relevant about acts and omissions is the way they determine

> the course of events to a foreseeable outcome, not the expenditure of energy. Omissions may exclude other possible outcomes to the same degree as acts ... The claim fails to distinguish ethics from physics. It confuses the question 'does blame attach to the deliberate determination of a course of events' with the question, 'was energy expended to bring about the result?'

Philosopher, Michael Tooley also rejects the notion that there is a morally significant distinction between killing and letting die, but he recognizes that there is a widespread feeling based on 'moral intuitions' - "that there is a morally significant difference between acting and refraining from acting." [134] He believes that this feeling may be based on confusion caused by a failure to distinguish between two separate questions: [135]

1. Is the distinction between killing and letting die morally significant in itself?
2. Are there other factors which make it generally the case that killing someone is more seriously wrong than intentionally letting someone die?

To answer the first question, Tooley constructs a moral fact situation similar to Rachels. In his example, two sons each wish their father's death, and each son decides to kill him. The first son places poison in his father's drink, which the second son discovers prior to his doing the same thing. Although the second son possesses an antidote, he stands by and watches his father drink the poisonous beverage. One son has killed, while the other has merely let the father die. Tooley argues that morally, both actions are equivalent. Given that both sons had the same intention, the second son's refraining from administering the antidote was just as wrong as the first son's killing. Thus, he concludes there is no morally significant distinction between active and passive euthanasia. [136]

Tooley's response to the second question is that in spite of there being no morally significant distinction between killing and letting die the presence of other factors will "tend to make it the case that an attempt to kill someone will generally be more seriously wrong than intentionally refraining from taking someone's life." These factors are "motive", "cost to the agent and/or society", and "the probability that death will result from one's action or inaction." [137]

First, he submits that "the motive of a person who kills someone is generally more evil than the motive of a person who lets someone die", since a person who lets another die may do so out of "laziness or apathy" which Tooley contends is not as seriously wrong as killing someone because the actor "wants" that person dead. [138]

Second, he explains that saving someone's life "may involve considerable risk to the agent or a very large expenditure of society's resources" which will rarely be the case in refraining from killing someone. [139]

Third, he argues that if someone performs an action that usually results in death, there is little chance that person will survive. On the other hand, if someone merely refrains from saving another's life, it still leaves open the possibility of survival. [140]

Tooley reasons that the presence of these factors generally means that it is worse to kill someone than to let them die, but he submits "[i]t is these factors that make the difference, rather than [a] difference between killing and letting die." [141]

In the moral fact situations cited by Tooley and Rachels, the intentions of the principal actors were identical, and these identical intentions formed the basis of their arguments that the distinction between killing and letting die was ethically irrelevant.

From this conclusion, Rachels then asserted, (and Tooley would agree) that the cessation of treatment was "the intentional termination of the life of one human being by another." 142 This point of view is shared by Magnet and Kluge who state: 143

> The decision-maker opts for non-action precisely because he believes non-action will lead to death. If the surrogate expected non-intervention to result in a continued existence of the neonate, he would feel morally obliged to interfere with the procedures designed to improve the quality of life ... The surrogate's intent inheres in his awareness of the impending death, and his decision not to interfere in spite of the expected death. Death is "intended", and is nonetheless so because the intent is executed by deliberate omission as opposed to action.

This argument assumes that the only possible reason a physician would cease to treat is because he believes that non-treatment will lead to death. Philosopher, Bonnie Steinbock refutes this argument. She points out that "[t]here are at least two situations in which the termination of life-prolonging treatment cannot be identified with the intentional termination of the life of one human being by another." 144 Her first example concerns a competent patient's right to refuse treatment and is not germane to the present discussion. In her second example, she cites the decision of a cancer specialist to cease painful anti-cancer treatment when the treatment is not improving the patient's condition and may be causing greater discomfort than the cancer itself. Steinbock contends that the physician's intention in this instance is not to end the patient's life but is rather a decision to provide the most appropriate treatment for the patient at that time.[145] Such treatment, she argues, may be considered "extraordinary" which can be contrasted with the "ordinary" care or treatment that a doctor would normally provide. A doctor's "[f]ailure to provide ordinary care", she contends, "can be seen as neglect, and can even be construed as the intentional infliction of harm, where there is a legal obligation to provide care." 146

Failure to perform surgery on a Down's Syndrome infant with a duodenal atresia is in Steinbock's view a failure to provide ordinary care. She agrees with Rachels that withholding treatment in this case is the intentional termination of life because the purpose of stopping the treatment (or not starting) is the infant's death. Nonetheless, there are other cases where the purpose is not to terminate the child's life but to avoid harmful and useless treatments.

A decision to cease aggressive or active treatment, in Steinbock's view, does not mean that a physician stops all treatment of the child and merely waits for it to die. Rather, the physician can continue to provide compassionate and caring treatment to make the rest of the child's life as pleasant and comfortable as possible. She argues that in this kind of situation withholding further active treatment cannot be considered to be "ethically equivalent" to killing the child. She concludes: [147]

> Certainly, it is worth pointing out that allowing someone to die can be the intentional termination of life, and that it be just as bad as, or worse than killing someone. However the withholding of life prolonging treatment is not necessarily the intentional termination of life, so that if it is permissible to withhold life prolonging treatment it does not follow that, other things being equal, it is permissible to kill. Furthermore, most of the time, other things are not equal.

A similar view has been expressed by Philosopher, Joseph Boyle. He agrees with Steinbock that Rachels' example of letting a Down's Syndrome infant with a duodenal atresia die is an intentional termination of the infant's life, but he points out that this case is not typical of all cases of letting die. He writes: [148]

> However, in many cases -- including those in which many regard letting die to be morally permissible -- treatment is withdrawn or withheld because it will be virtually useless or because of the great pain the treatment will cause the patient or for some similar reason and not because the person's life has been judged unworthy of living, or because someone wished not to take care of the patient.

Boyle argues that when treatment is withdrawn because it causes great pain or is futile it does not mean that the doctor intends the death of the patient, as would necessarily be the case if he decided to kill the patient. In such a case, the doctor may foresee the patient's death and accept it, but he does not seek to bring it about.

Boyle also rejects Rachels' contention (which is also based on the example of a Down's Syndrome infant with an intestinal blockage) that in many cases letting die is more painful than killing a patient quickly and painlessly. He suggests that this example is not representative of all cases, since he points out that treatment may be withdrawn because the treatment itself may be causing pain and be of little benefit to the patient. In these cases, letting a patient die by withdrawing treatment is based on a humanitarian concern of preventing suffering. [149]

Rachels and Tooley's essays clearly show that in some cases a decision to let a child die is morally equivalent to the decision to kill that child. Thus, when the child's death is intended, it is irrelevant whether this intention is carried through by an omission or by active intervention. In this narrow range of cases, the moral distinction between active and passive euthanasia breaks down. If this were true of all cases of killing and letting die as Rachels and Tooley (and Magnet and Kluge) assume there would be no point in retaining the legal distinction between killing and letting die.

In any event, the law does not support this artificial distinction in the example Rachels cites. A doctor who starved an infant to death by failing to perform a relatively simple surgical procedure would be guilty of culpable homicide under Canadian law as would a doctor who administered a lethal injection, since the law is concerned with the actor's intention -- and in each example, the physician intended the infant's death.

However, as Steinbock and Boyle have pointed out the active/passive euthanasia distinction is relevant in those cases where the intention in letting die differs from the intention in killing. In cases of letting die where death is foreseen but is not intended, the distinction between killing/letting die or active/passive euthanasia is morally relevant, and the law recognizes the distinction. By retaining this distinction in the law, whereby active euthanasia or killing is always forbidden while some (but not all) cases of letting die or passive euthanasia are permitted, the law encourages respect for human life as well as compassion in cases where treatment may be painful and futile. For these reasons, the traditional distinction between active and passive euthanasia should continue to be recognized and maintained in our law.

Other commentators who favor legalizing euthanasia have directed their attention to the distinction between voluntary and involuntary euthanasia. In their view, if a person wants to die, it is irrelevant whether death is caused by killing or by letting die. However, other writers have argued that, even if neither active or passive euthanasia is wrong in such cases, legalizing voluntary active euthanasia would lead to undesirable consequences. These respective positions are illustrated by the writings of Glanville Williams and Yale Kamisar and will be examined in the following section.

B. The Debate Between Williams and Kamisar

1. Williams Proposal

Glanville Williams in his book, The Sanctity of Life and the Criminal Law, advocated legislation which would permit a physician to actively kill an adult patient who requested it, provided the patient suffered from a "painful and incurable" illness and the physician consulted with one other physician prior to performing the act.

Williams was opposed to the legal uncertainties that doctors faced in this area of the law and he attributed much of the condemnation of euthanasia to outmoded religious convictions. His ethical arguments in favour of euthanasia were based upon two values: The first value was the prevention of cruelty. He argued that it was "cruel to allow a human being to linger for months in the last stages of agony, weakness and decay" and cruel to his loved ones who had to witness his agony.[150] The second value involved was that of liberty. Williams contended that the incurably ill, competent patient had the right to have his life terminated, if he so chose.

Although Williams restricted his proposal to "voluntary" euthanasia (where a competent adult requests that he be killed) he addressed the question of "involuntary" euthanasia of seriously handicapped infants and elderly individuals suffering from senility. In the latter case, he wrote that the problem had not yet reached serious enough proportions that would warrant a change in attitude toward the "sanctity of life of the aged." 151 However, he was much more optimistic about the possibility of allowing involuntary euthanasia for "hopelessly defective infants" which he perceived to be fraught with less difficulty than euthanasia of the senile. He wrote: 152

> While the Euthanasia Society of England has never advocated this, the Euthanasia Society of America did include it in its original program. The proposal certainly escapes the chief objection to the similar proposal for senile dementia: it does not create a sense of insecurity in society, because infants cannot, like adults, feel anticipatory dread of being done to death if their condition should worsen. Moreover, the proposal receives some support on eugenic grounds, and more importantly on

> humanitarian grounds both on account of the parents, to whom the child will be a burden all their lives, and on account of the handicapped child itself. (It is not, however, proposed that any child should be destroyed against the wishes of its parents). Finally, the legislation of euthanasia for handicapped children would bring the law in closer relation to its practical administration, because juries do not regard parental mercy-killing as murder. For these various reasons the proposal to legalize humanitarian infanticide is put forward from time to time by individuals. They remain in a very small minority, and the proposal may at present be dismissed as politically insignificant.

2. Kamisar's Rebuttal

Yale Kamisar raised three main objections to Williams' mercy-killing proposals. First, he argued there was the possibility of mistakes or abuse under Williams' policy. He cited the problems of faulty or incorrect diagnoses being made. Second, there was the problem of being able to know whether the patient's choice was truly voluntary when a patient's mind was "crazed by pain or drugs". [153] His third argument was that proposals for voluntary euthanasia would be extended (or constitute the opening wedge) to programs of involuntary euthanasia. In raising the "wedge" argument, Kamisar pointed out that many of the proponents of voluntary euthanasia, including Williams himself, were "not adverse" to involuntary euthanasia. He therefore reasoned: 154

> ... it is hardly reassuring for Williams to cite the fact that only a "very small minority" has urged euthanasia for "hopelessly defective infants" as the only reason for not pressing for such legislation now I read Williams' comments on defective infants for the proposition that there are some very good reasons for euthanizing defective infants, but the time is not yet ripe. When will it be? ... after a voluntary law is on the books and public opinion is sufficiently "educated?"

The wedge principle was particularly relevant to the issue of involuntary euthanasia of defective infants in Kamisar's view, because it had already occurred in Nazi Germany. He noted that while Hitler was forced to reduce his adult euthanasia program, the killing of mentally and physically defective children continued on unimpeded until the end of the war, while the definition of 'children' continued to expand.

3. Critiques of Kamisar's Wedge Argument

One objection to Kamisar's argument stems from his use of the Nazi analogy which is allegedly based upon a misunderstanding of the Nazi concept of euthanasia. Helga Kuhse and Peter Singer in their book, Should the Baby Live?, discuss this "spectre of Nazism" which is commonly raised by those who oppose active euthanasia. 155 Many of these writers refer to an article entitled "Medical Science under Dictatorship", which was published in the New England Journal of Medicine, in 1949. The author, Dr. Leo Alexander, who served as a psychiatrist with the United States Council on War Crimes in Nuremburg, contended that it was the Nazi euthanasia program which ultimately led to the mass genocide which occurred under the Nazi regime. In a often-quoted passage, he wrote: 156

> Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basis attitudes of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted, and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind

> received its impetus was the attitude toward the non-rehabilitable sick.

Kuhse and Singer argue that Alexander has "badly misunderstood the Nazi terminology". In support of this claim they cite the comments made by Professor Lucy Dawidowicz, a noted historian and author, which were presented at a conference on 'The Proper Use of the Nazi Analogy in Ethical Debate' sponsored by Hastings Center, in 1976. Professor Dawidowicz explained that taking terms that the Nazi's used, such as euthanasia and translating them literally can lead to our misconstruing them, when they are used in a different sense than the Nazi's used them.

She pointed out that the concept of 'euthanasia' and the programs headed under its auspices were the cornerstones of Nazi racist policies. The central theme of these policies was a concern with the ultimate 'purity' of the race, which was embodied in the theory of the Volk, a word meaning 'people' or 'nation'. Individuals who were harmful to racial health meaning racial purity were classified as 'valueless life'. Professor Dawidowicz concluded: [157]

> ... The 'valuelessness' of such life was measured in terms of the health of

> the Volk, itself an abstract concept, not a physical reality. This health had no bearing on individual health, on family health, even on public health, or the health of society.

Drawing on Professor Dawidowicz's remarks, Kuhse and Singer contend that Alexander misunderstood the Nazi's concept of a "life worth living", and they argue that this "misunderstanding vitiates his attempt to use the historical experience of Nazism as an argument against euthanasia as we now understand the term." [158] They believe this to be the case, since our society does not believe in a concept of racial purity, therefore they argue that allowing the euthanasia of defective infants would not lead to Nazi-like atrocities.

This long and rather convoluted argument fails to refute Alexander's proposition that the "slippery slope" the Nazi's embarked upon stemmed from the notion that there are some lives that are not worthy to be lived. Whether this view had its origins in a concept of 'racial health' or 'physical health' would appear to be irrelevant since each view holds that some lives are not worth living.

A more convincing rebuttal to Kamisar's Nazi analogy is made by Richard Sherlock who suggests that our cultural, political, historical and legal traditions are very different from those which prevailed in Nazi Germany during the years in question and that in light of these many differences it is difficult to accord the Nazi analogy much weight.[159]

Apart from its specific application to the claim that legalizing euthanasia will lead to Nazi-like atrocities, is the wedge principle a valid argument against legalizing certain forms of euthanasia? Richard Sherlock argues that the principle is. However, he points out that Kamisar should not have raised the wedge argument in the form of a prediction since he states:[160]

> ... one need not predict that the retarded and the insane will be disposed of; one need only show that the mooted position logically leads to untenable conclusions, if fairly applied to all relevantly similar cases ... If any proposal cannot meet such a test of fair application without repugnant results, it must be discarded.

If this test were to be applied to the euthanasia proposals suggested by the ethicists whose views have been previously discussed, it is clear that the arguments which have been raised in favor of legalizing infant euthanasia would apply with equal cogency to other population groups, for example, comatose patients, severely retarded adults or those suffering from senility. Many of these individuals would not possess the qualities necessary to attain a 'meaningful' life such as that contemplated by Fletcher or Brandt. For others, according to Weir's best interests test, death may be preferable to an unbearable continued existence. If death is to be preferred for infants in these cases, it is equally desirable and in accordance with the principle of justice - that others suffering similar conditions who have passed infancy should have the right or obligation to be the subject of euthansia as well.

Furthermore, many non-infant human beings lack the capacities necessary for personhood as envisioned by Tooley and Singer. However, Tooley attempts to restrict the expansion of his argument by allowing that someone who may not currently possess the properties he deems necessary for personhood may still have a serious right to life, if he had "possessed at some time in the past" these necessary properties. This may avoid the inclusion of comatose patients or the senile into groups who may be subject to euthanasia with impunity but many mentally handicapped individuals would fail to meet his criteria and could therefore be justifiably terminated.

Kuhse and Singer's 'personhood' theory contains no such restriction. The logical extension of their analysis would include all other non-infants who lack the capacities they deem necessary for personhood. Kuhse and Singer are clearly aware of the potential implications of their theory. In the preface of their book they issue a disclaimer in which they explain that their discussion and conclusions are meant only to apply to disabled infants and that they do not consider life or death decisions for handicapped non-infants in the same way. This explanation in the front of the book does not save their theory since if it is applied to these "relevantly similar cases" there is no reason not to apply euthanasia to 'non-persons' who are no longer infants.

However, Kuhse and Singer propose a response to the objection that Sherlock makes. They suggest that although their theory could logically apply to other 'non-persons' past infancy - practically the line allowing euthanasia could be drawn wherever we chose to draw it. The mere fact that we are on a slippery slope does not mean that we must necessarily slide down it. To illustrate this point, they refer to the comments made by Clifford Grobstein in his book, From Chance to Purpose, who writes: [161]

> As long as our purposes are clearly spelt out, and we know how far we are willing to go, there is no reason to fear slippery slopes. Any new proposal that lies outside our original purposes will have to be considered afresh, and at that point we can always refuse to take the further step.

The wedge argument as stated by Richard Sherlock is an effective rebuttal to those who wish to legalize euthanasia for certain groups. If euthanasia (whether active or passive) is morally right for one group of patients it would be morally wrong to arbitrarily deny the right to other groups as Grobstein's remarks imply.

It is the writer's view that "active" euthanasia (direct killing) should not be legalized. However, "passive" euthanasia should be permitted in a limited number of cases. For the adult terminal patient for whom aggressive therapies can do nothing but prolong inevitable death, such treatment should be permitted to be withdrawn. Similarly in the neonatal context, life-saving or aggressive treatments which are futile and/or will only lead to pain and suffering with a minimal chance for success should also be permitted to be withdrawn. This does not mean that medical care ceases, but rather that it is directed to ensuring the patient's comfort rather than mere survival. Such an approach shows respect for human life while at the same time recognizes that there are some conditions which are beyond the pale of medical science.

CHAPTER 3 ENDNOTES

1. Paul Taylor, "Utilitarianism," in Contemporary Issues in Bioethics, eds. Tom L. Beauchamp and LeRoy Walters (Belmont, California: Wadsworth Publishing Company, Inc. 1978), p.12.

2. Joseph Eliot Magnet and Eike-Henner W. Kluge, Withholding Treatment from Defective Newborn Children (Cowansville, Quebec: Brown Legal Publications, Inc., 1975), p.144.

3. Supra n.1 at 12.

4. William K. Frankena, "Deontological Theories," in Contemporary Issues in Bioethics, eds. Tom L. Beauchamp and LeRoy Walters (Belmont, California: Wadsworth Publishing Company, Inc. 1978), p.23.

5. See for example, Jeremy Bentham, An Introduction to the Principle of Morals and Legislation (New York: Humanities Press, 1970); John Stuart Mill, Utilitarianism, On Liberty, and Essay on Bentham, with an Introduction by Mary Warnock (Cleveland: World Publishing Co., 1962).

6. Supra n.2 at 145.

7. Supra n.1 at 15.

8. R.M. Hare, Utilitarianism," in Encyclopedia of Bioethics, ed. Warren T. Reich, vol.1 (New York: The Free Press, 1978), p.426.

9. Supra, n.1 at 19. See also Joseph Fletcher, "Situation Ethics," in Encyclopedia of Bioethics, ed. Warren T. Reich, vol.1 (New York: The Free Press, 1978), p. 422.

10. Supra n.2 at 145.

11. Id., at 145.

12. Both the rule utilitarian and the deontologist would assign a ranking to the rule or duty to preserve life and the rule or duty not to cause pain and suffering. However, the rule

utilitarian would base his decision on the consequences which would generally flow from applying these rules, while the deontologist would base his decision on a determination of the inherent rightness of the action.

13. Fletcher, supra n.9 at 424.

14. Leonard J. Weber, Who Shall Live? (New York: Paulist Press, 1976), p.p. 41-42.

15. Immanuel Jakobovits, "Jewish Views on Infanticide," in Infanticide and the Value of Life, ed. Marvin Kohl (Buffalo, New York: Prometheus Books, 1978), p.27.

16. Id. at 28-29.

17. Id. at 30.

18. Paul Ramsey, Ethics at the Edges of Life (New Haven and London: Yale University Press, 1978), p.192.

19. Id., at 188.

20. Id. at 216.

21. Richard Sherlock, Preserving Life (Chicago: Loyola University Press, 1987), p.96.

22. Id., at 96.

23. M. Pabst Battin, "The Least Worst Death," (1983) Hastings Cent Rep, 13.

24. Supra n.21 at 45.

25. Id., at 57.

26. Id., at 73.

27. Id., at 116.

28. Edward W. Keyserlingk, Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law. Protection of Life Series, Study Paper. Law Reform Commission of Canada (Ottawa: Minister of Supply and Services, 1979), p.p. 405.

29. Warren T. Reich, "Quality of Life and Defective Newborn Children: An Ethical Analysis," in Decision-Making and the Defective Newborn, ed. Chester A. Swinyard (Springfield, Ill.: Charles C. Thomas, 1977), p.506.

30. Robert F. Weir, Selective Nontreatment of Handicapped New-borns: Moral Dilemmas in Neonatal Medicine (New York and Oxford: Oxford University Press, 1984), p. 212.

31. Pope Pius XII, "The Prolongation of Life," in Death, Dying and Euthanasia, eds. Dennis J. Horan and David Mall (Washington, D.C.: University Publications of America, Inc., 1977), p 284.

32. See for example, Sissela Bok, "Ethical Views," in Encyclopedia of Bioethics, ed. Warren T. Reich, vol.1 (New York: The Free Press, 1978), p.p. 270-77; Kuhse, Helga and Peter Singer, Should the Baby Live? (Oxford: Oxford University Press, 1985), p.p. 30-37.

33. Gerald Kelly S.J., Medico-Moral Problems (St. Louis: The Catholic Hospital Association, 1958), p.129. Reprinted in Weir, supra n.30 at 212.

34. Supra n.14 at 90.

35. Supra n.29 at 507.

36. Warren T. Reich and David E. Ost, "Ethical Perspectives in the Care of Infants," in Encyclopedia of Bioethics, ed. Warren T. Reich, vol.1 (New York: The Free Press, 1978), p.728; Weber, supra n.14 at 92.

37. Id., at 95.

38. Id., at 97.

39. Norman Fost, "Ethical Issues in the Treatment of Critically Ill Newborns," (1981) 10 Pediatr Ann, p.18.

40. Supra n.30 at 213.

41. Law Reform Commission of Canada. Euthanasia, Aiding Suicide and Cessation of Treatment, Protection of Life Series, Working Paper 28 (Ottawa: Minister of Supply and Services, 1982), p.36.

42. President's Commission for the Study of Ethical Problems in Medicare and Behavioral Research, Deciding to Forego Life- Sustaining Treatment (Washington, D.C.: U.S. Government Printing Office, 1983), p.p. 88-89.

43. Supra n.39 at 18.

44. Supra n.21 at 108. See also Kuhse and Singer, supra n.32 at 30-37, who argue that those who use the distinction "correctly take into account the poor quality of such a life." (p.37) They conclude that those who invoke the distinction are abandoning the view that all life is of equal worth.

45. Paul Ramsey, unpublished talk, quote printed in Death, Dying and Euthanasia, eds. Dennis J. Horan and David Mall (Washington, D.C.: University Publications of America, Inc. 1977), p.214.

46. Supra n.39 at 18.

47. Kuhse and Singer, supra n.32 at 37.

48. Supra n.2 at 152.

49. Id., at 153.

50. Id., at 153.

51. Id., at 162.

52. Id., at 162.

53. Id., at 166.

54. Id. at 167. See also, Eike-Henner W. Kluge, The Ethics of Deliberate Death (Port Washington, N.Y.: Kennikat Press Corp., 1981), p.p.81-93.

55. Id., at 167.

56. Id., at 168.

57. Id., at 168-69.

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59. Id., at 185.

60. Id., at 187.

61. Id., at 187.

62. Id., at 188.

63. Id., at 188.

64. Id., at 189.

65. Supra n.30 at 164.

66. Richard A. McCormick "To Save or Let Die - The Dilemma of Modern Medicine," (1974) 229 JAMA, 172. Article reprinted in Thomas A. Mappes and Jane S. Zembaty, eds., Biomedical Ethics 2nd ed. (New York: McGraw-Hill Book Company, 1986), p.429.

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68. Id., at 431.

69. Id., at 432.

70. Reich, supra n.29 at 502-03; Weber, supra n.14 at 82-86.

71. Supra n.36 at 732.

72. Joseph Fletcher, "Infanticide and the Ethics of Loving Concern," in Infanticide and the Value of Life, ed. Marvin Kohl (Buffalo, N.Y.: Prometheus Books, 1978), p.20.

73. Id., at 20.

74. Joseph Fletcher, "Indicators of Humanhood: A Tentative Profile of Man," (1972) 2 Hastings Cent Rep, 1-4.

75. Joseph Fletcher, "Four Indicators of Humanhood - The Enquiry Matures," (1974) 4 Hastings Cent Rep, 6-7.

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77. Supra n.29 at 493.

78. Supra n.29 at 493.

79. Supra n.14 at 75.

80. Richard Brandt, "Defective Newborns and the Morality of Termination," in Infanticide and the Value of Life, ed. Marvin Kohl (Buffalo, N.Y.: Prometheus Books, 1978), p.49.

81. Id., at 49.

82. Id., at 49.

83. Supra n.21 at 80.

84. Kuhse and Singer, supra n.32 at 121.

85. Michael Tooley, "Abortion and Infanticide," (1973) 2 Phil and Public Affairs, 44.

86. Id., at 44.

87. Id., at 49.

88. Id., at 60-62.

89. Michael Tooley, Abortion and Infanticide (New York: Oxford University Press, 1983), p.p. 411-12.

90. Id., at 411-12.

91. Kuhse and Singer, supra n.32 at 121. See also, John Lachs, "Humane Treatment and the Treatment of Humans," (1976) 294 New Eng J Med, 838.

92. Id., at 122.

93. Id., at 123.

94. Id., at 131.

95. Id., at 131.

96. Id., at 135.

97. Peter Singer, Practical Ethics (Cambridge University Press, 1979), p. 134.

98. Supra n.30 at 181.

99. Id., at 181.

100. Id., at 181.

101. Supra n.36 at 729.

102. Id., at 729. For example, should animal experimentation be permitted using chimps or gorillas or other animals who are "persons" which would benefit man?

103. Supra n.30 at 171.

104. Id., at 200.

105. Id., at 210.

106. The practical application of Weir's theory will be discussed in Chapter Four.

107. Id., at 221.

108. Joel E. Frader, "Selecting Neonatal Ethics," (1985) 20 Soc Sci Med, 1089.

109. Thomas H. Murray, "Why Solutions Continue to Elude Us," (1985) 20 Soc Sci Med, 1106.

110. Id., at 1107.

111. H. Tristram Engelhardt Jr., "Ethical Issues in Aiding Death of Young Children," in Biomedical Ethics, eds. Thomas A. Mappes and Jane S. Zembaty, 2nd ed. (New York: McGraw-Hill Book Company, 1986), p.435.

112. Id., at 436.

113. H. Tristram Engelhardt Jr., "Euthanasia and Children: The Inquiry of Continued Existence," (1973) 83 J Pediatr, 170.

114. Cataford v.Moreau (1978) 114 D.L.R. (3d) 585 (Que. Sup. Ct.); McKay v. Essex A.H.A. [1982] 2 W.L.R. 890 (C.A.).

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116. Id., at 438.

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125. *Supra* n.21 at 90-91.

126. *Supra* n.122 at 86.

127. Bok, *supra* n.32 at 269.

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130. Id., at 66.

131. Id., at 67.

132. Supra n.2 at 177.

133. Id., at 177-78. See also Kuhse and Singer, supra n.32 at 80-84.

134. Michael Tooley, "An Irrelevant Consideration: Killing versus Letting Die," in Killing and Letting Die, ed. Bonnie Steinbock (Eaglewood Cliffs, New Jersey Prentice Hall, Inc. 1980), p.59.

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136. Id., at 61.

137. Id., at 59.

138. Id., at 59.

139. Id., at 59.

140. Id., at 59.

141. Id. at 60.

142. Supra n.127 at 66.

143. Supra n.2 at 178.

144. Bonnie Steinbock, "The Intentional Termination of Life," in Killing and Letting Die, ed. Bonnie Steinbock (Eaglewood Cliffs, New Jersey: Prentice Hall, Inc. 1980), p.71.

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146. Id., at 72.

147. Id., at 76.

148. Joseph M. Boyle Jr., "On Killing and Letting Die," (1977) 51 New Scholasticism, 438.

149. Id., at 445.

150. Glanville Williams, "Mercy-Killing Legislation -- A Rejoinder," in Contemporary Issues in Bioethics, eds. Tom L. Beauchamp and LeRoy Walters (Belmont, California: Wadsworth Publishing Company, Inc. 1978), p.318.

151. Glanville Williams, The Sanctity of Life and the Criminal Law, James S. Carpentier Series (New York: Alfred A. Knopf, Inc., 1957), p. 348.

152. Id., at 349-50.

153. Yale Kamisar, "Some Non-Religious Views Against Proposed 'Mercy-Killing' Legislation," (1958) 42 Minn L Rev, 969. Article reprinted in Death, Dying and Euthanasia, eds. Dennis J. Horan and David Mall (Washington, D.C.: University Publications of America, Inc., 1977), p.422.

154. Id., at 464 and 466.

155. Kuhse and Singer, supra n.32 at 93.

156. Leo Alexander, "Medical Science Under Dictatorship," (1949) 241 New Eng J Med, 44.

157. Supra n.32 at 94.

158. Id., at 95.

159. Supra n.21 at 122.

160. Id., at 122.

161. Clifford Grobstein, From Chance to Purpose: An Appraisal of External Human Fertilization (Reading, Mass.: Addison-Wesley, 1981) p. 71. Reprinted in Kuhse and Singer, supra n.32 at 95.

Chapter 4: Criteria Guiding Decisionmakers

I. Introduction

The preceding chapters have shown that prevailing standards of medical practice do not require that all defective infants be given life prolonging treatments nor does Canadian law impose such a requirement. However, it is unclear which infants may be denied life-saving treatment and under what circumstances.

Part of the problem is due to the wide range of cases which are found within neonatal practice. Yet simplistic solutions, such as requiring treatment in all cases or allowing parents and physicians total discretion in making such decisions fail to address the complex moral issues that are involved in these cases. Equally unsatisfactory, from a practical standpoint, are the personhood theories which employ the moral and legal fiction of "non-personhood", for vaguely defined classes of infants in order to deny such infants the legal protections accorded to "persons" in our society. These theories offend "moral commonsense" and violate the principles upon which medical practice and the law are based.[1]

What is needed is the development of substantive criteria in the form of clearly articulated guidelines which would specify the circumstances and conditions in which nontreatment decisions can acceptably be made.

John Robertson, an American law professor, has pointed out that unless such criteria are developed, "the current haphazard, arbitrary pattern of selection for nontreatment is likely to continue. [2] As a result, undesirable treatment decisions will continue to be made which may fail to consider infants' best interests. For instance in some cases, decisions to withdraw treatment are made prematurely, or without complete information, according to the personal values of parents and/or physicians, while in others, infants may be harmed by overtreatment.

The criteria for nontreatment decisions should satisfy three conditions: the first, and foremost requirement is to protect the child's best interests. The interests of others should be considered but should not be allowed to override the infant's interests. Second, the criteria should provide clear guidelines which are consistent with good medical practice and current law. It is also important that the criteria be flexible enough to allow for changes in medical practice and to deal with unusual situations. A third requirement is that the guidelines should not violate widely held moral values of society. [3] Although there is no obvious moral consensus regarding the treatment/nontreatment of severely defective infants, society has always sought to preserve human life and to protect its weaker, more helpless members.

The reasons which are most commonly given in order to justify the withdrawal of treatment from defective infants are those based upon a quality of life philosophy. However, these theories fail to satisfy the three conditions suggested above.

Quality of life approaches often consider "quality of life" not only in terms of the infant's condition, but in terms of the infant's impact on others. [4] Thus, the infant's interest in life may be subordinated to the interests of others in some cases.

Since a "poor" or "meaningful" quality of life has never been adequately defined, these theories do not provide clear or consistent guidelines to decisionmakers. There is not only disagreement as to which factors should be assessed in determining the infant's potential quality of life but also disagreement as to the degree of impairment or suffering that would result in such a poor quality of life that treatment could justifiably be withheld.

Furthermore, since quality of life approaches assume that certain lives are not worth living or saving, they imply that some lives are worth less than others. This philosophy flies in the face of the longstanding moral traditions of our society which hold that all lives are of equal value. In addition, decisions based upon a quality of life approach involve factors that legally should not enter a treatment decision as illustrated by the remarks made MacKenzie, J. in the Stephen Dawson case: 5

> I do not think that it lies within the perogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of life of that person's life to be so low as not to be deserving of continuance.

On the other hand, the best interests of the child approach gives "full weight" to the infant's interests. Treatment may only be withheld if it will not benefit or will harm the child. The interests of others cannot override the child's right to receive beneficial treatment.

The best interests of the child approach provides greater clarity and certainty to the decisionmaker since the primary factor in determining the basis for treatment is the infant's medical condition and whether treatment would on balance benefit or harm the infant. This is far less ambiguous than speculating about the "quality of an infant's life" and is consistent with traditional medical norms and present law.

Finally, in balancing the benefits and harm of possible treatments the best interest standard avoids passing judgments on the 'worth' of an individual life which is in keeping with widely held moral values. Thus, the best interests of the child approach satisfies the three conditions specified above and provides the best ethical basis for the formulation of substantive criteria to guide decisionmakers in making treatment/nontreatment decisions for defective infants.

II. The Factual Basis of Decisionmaking

The major difficulty that will inhibit the development of any proposed criterion of nontreatment in neonatal medicine is the dual problem of diagnostic and prognostic uncertainty.

A. Accurate Diagnosis

Robert Weir comments that there are two reasons that accurate diagnosis is thought to be an even greater necessity in neonatal medicine than in other areas of medical practice: [6]

> Newborns present neonatologists and other pediatricians with a much greater variety of medical problems than do patients seeing other physicians, and neonatal patients with severe congenital anomalies are much more vulnerable to life-threatening complications and death than are older patients who are less susceptible to apneic spells, cyanosis and infection.

An accurate diagnosis is important for determining the management of each case. For example, a diagnosis of a Grade 4 bilateral intraventricular hemorrhage calls for a less aggressive response than would a less serious Grade 3 bilateral ventricular hemorrhage. [7]

Accurate diagnoses are also important since certain diagnoses "carry a fatal prognosis." [8] For conditions such as anencephaly and renal agenesis there are no effective treatments available, therefore once the diagnosis is confirmed only palliative treatment need be given.

Pediatrician Norman Fost, highlights the importance of accurate diagnoses in clinical practice: [9]

> Good ethics start with good facts and sound ethical reasoning will not rescue a decision based on false assumptions.

B. Prognostic Uncertainty

A problem of even greater magnitude in neonatal medicine is prognostic uncertainty. It is undoubtedly the most critical problem that neonatologists and pediatric specialists face. While physicians are often able to make accurate diagnoses of infants' conditions, there is much less certainty when it comes to forecasting the probable outcome of the diagnosed condition.

Medical commentators repeatedly stress that ethicists and lawyers often assume that much greater certainty exists in medicine with respect to certain conditions, than actually does. Joel Frader, a tertiary care pediatrician, claims that "uncertainty and emotion are the central issues in neonatal practice." [10] Uncertainty arises because the range of neonatal disabilities is very wide as is the range of disability within particular conditions. Thus, the mere presence of Down's Syndrome or extreme prematurity does not foretell the extent of a child's disability as Frader explains: [11]

> At birth, or in the weeks and months following, one cannot know whether an infant with Down's Syndrome eventually will have near normal mental capacity or be utterly dependent on others for even basic needs ... In the recurrent cases of Down's Syndrome with anomalies that are lethal without surgery, it is the possibility of profound retardation, perhaps coupled with chronic heart failure, recurrent infections and generalized failure to thrive that plague some doctors and many parents.

He also describes the uncertainty which occurs in treating extremely premature infants: [12]

> In the first hours and days, neonatologists cannot predict whether very small premature infants will develop disabling chronic lung disease (bronchopulmonary dysplasia), suffer brain injury from severe intercranial hemorrhage, have life-threatening gastrointestinal difficulties or mature with relatively few problems ... It is the prospect of the blind and/or deaf 'graduate' of neonatal intensive care who also has severe spasticity of muscles that gives pause to many young pediatricians called to resuscitate a 26 - 28 week gestation, 700 gm. infant.

Frader contends that, "we simply do not yet know how to predict outcome," expressing impatience with lawyers and ethicists who have never "lived with and felt responsible for situations that might have been prevented" and who calmly rationalize and reason out the emotional aspects involved in such decisions. [13] He concludes: [14]

> Moral reasoning and legal process that do not account for the unknowable and the human response to uncertainty are incomplete.

One of the problems neonatologists face is that many of the infants they care for, such as those suffering from extreme prematurity, have only recently been successfully treated and there has not yet been time for long-range studies necessary to measure the effects on morbidity. This problem is further compounded by the fact that therapies are always changing in neonatology and new therapies are often tried before the long-range testing of earlier therapies has been completed. [15]

Physicians themselves may contribute to the problem by prematurely applying prognostic labels to infants such as "hopelessly" or "terminally" ill or "non-viable" prior to completing the diagnostic work necessary to make such an assessment and the labels may become self-fulfilling prophecies. [16] Other "physician problems" discussed by Robert Weir involve the unwillingness of some physicians to assess the prognosis of individual infants suffering from a specific diagnostic condition as well as the tendency of some physicians to exaggerate the gravity of an infant's condition in order to appear "omniscient when the child dies or omnipotent ... in the event the child survives with vigorous treatment." [17]

Another issue in neonatal medicine relating to uncertainty is the use of statistical predictions. How should statistics affect decisions to treat or withhold treatment from a particular infant? [18] Statistical predictions show various degrees of risk for infants in certain categories. While it may be possible to tell what the degree of risk is for a particular infant, there are always "miracle babies" who defy expectations. Moreover, physicians assess statistics differently depending upon their own values and experiences. [19]

Dr. David K. Stevenson, the associate director of nurseries at Stanford University Medical Center, suggests that statistics are valid for populations but not individuals since a particular infant may be the exception to the rule. He argues, "[i]f you use only categories to make decisions you assume responsibility for having, essentially, executed a normal person some of the time." [20]

Other physicians disagree with this view. Since there is very little certainty in medicine, they argue, physicians always have to use their best judgment in the face of uncertainty. Ignoring the risks and probabilities can lead to the salvaging of many infants through aggressive therapies for whom continued existence may be a terrible burden amounting to "a living death". [21]

Although life and death decisions in medicine must often be made in the absence of complete data, Fost maintains that prognostic uncertainty, [22]

> can be reduced by consultation, a therapeutic trial, or a limited period of observation - the best course is usually to avoid making an irreversible decision based on wrong information.

Though prognostic uncertainty will often undermine the efficacy of any proposed criterion of nontreatment, the development of guidelines can in many instances serve to narrow the range of uncertainty in decisionmaking.

III. Determining the Infant's Best Interests

A. Ethical Guidelines

In attempting to assess the best interests of a particular infant the decisionmaker must have a standard by which the infant's best interests can be determined. One proposal which has been suggested by ethicist Robert Weir, is through an application of the principles of beneficence and nonmaleficence which have traditionally governed medical practice. Weir explains: [23]

> The principle of beneficence requires that moral agents further the important interests of other persons whenever their proximity and efficient alternatives allow them to do so with only minimal risk to themselves.

While, on the other hand, [24]

> The principle of nonmaleficence (primum non nocere) is the more stringent of the two principles and requires that moral agents avoid intentionally or negligently harming other persons.

For the majority of infants who become patients in neonatal nurseries, the principle of beneficence governs their care. Continued living is in the best interests of most infants and therefore lifesaving treatment is medically and ethically required on the part of physicians who are providing their care.

However, modern medicine now has the ability to keep alive many infants with severe anomalies and conditions which were previously incompatible with life. For some of these infants it is not clear whether continued existence represents a benefit or a burden to be endured. As Weir points out, many of these infants will face lives of agonizing pain, suffer from irreversibly deteriorating medical conditions and severe neurophysiological disabilities. [25] In these rare cases, the principle of nonmaleficence may impose a duty on physicians not to harm such infants with the advanced medical therapies at their disposal.

This view of the operative effect of the principle of nonmaleficence in medical practice is contrary to its traditional interpretation in medicine. Traditionally, medicine has perceived death as the most serious harm that could befall an individual and physicians have since the time of Hippocrates been forbidden to kill or to perform actions that would assist in another person's death. [26]

In recent times this perspective on death has been called into question because of the ability of medical technology to maintain patients in comatose and vegetative states. Many adults consider life in such a state to be worse than death and, as a result, there has been a growing recognition that death is not always the greatest harm that could befall an individual.

For most competent adults their own death would be ranked near the top on a list of harms that could befall them. However, other experiences or combinations of experiences are considered to be more harmful than death. These experiences would be ranked differently by different individuals according to their own personal values. Accordingly, just as it would be possible for a rational adult to determine that death would be in his or her own best interests, it is possible to conceive that death could also be in the best interests of certain anomalous infants.

Weir therefore suggests that a similar ranking of harms could be used by a proxy decisionmaker in assessing whether treatment would be in an infant's best interests. He envisions a detriment-benefit calculation involving a balancing of the harms (of the proposed treatment plus the infant's condition) to the benefits that would accrue from such treatment. He explains that some system of ranking of harms is necessary in order to provide a "framework" for determining whether a harm or combination of harms would render continued life a greater harm than death for a seriously ill or defective newborn.[27]

Before constructing such a framework, two issues must be addressed by the decisionmaker. First, what harms or burdens may be included in calculating the benefits and burdens of the infants? Second, from whose viewpoint should these burdens be assessed? Should it be from the perspective of a rational adult, the "reasonable" person or from the perspective of the handicapped infant?

1. Harms and Benefits in the Neonatal Context

The term "harm" has many connotations. Individuals are capable of being harmed in various ways. Therefore it is necessary to clearly understand what is meant by "harm" in the neonatal context.

One aspect of harm which is relevant to infants is physical pain. Within neonatal nurseries:[28]

> [t]he babies are constantly subject to the routine of pain of therapy - needles to draw blood, to start I.V. lines, to introduce antibiotics, even the nurse's daily thumpings of the babies to clear their trachea.

The infants also suffer pain because of their handicaps and conditions. Another type of harm is emotional or psychological harm. However, there is disagreement over whether infants can suffer from this kind of harm. Frohock claims that infants can suffer some emotional pain, such as "fear, embarassment or humiliation", [29] while Weir contends that newborns cannot suffer in this way "because of their lack of psychological development." [30] Whether infants can suffer from emotional harm or not, it is clear that it may be considered a minor harm at this stage of life in comparison to harm caused by physical pain.

In addition to physical and emotional harm, Frohock submits that individuals can be harmed by deprivation, being deprived of "all future experiences", by being deprived of life. [31] A broader notion of harm is suggested by Weir involving harm to a person's "interests, which may include among others, their health, property, reputation, domestic relations, privacy or life itself." [32] Clearly, an infant cannot suffer harm to its reputation or privacy, or domestic relations. The relevant harms in the neonatal context therefore, are physical pain, harm to health and deprivation.

However, all medical treatment causes some degree of harm to a patient. The harm is justifed only if the benefits of treatment exceed the harm or suffering caused by that treatment. Within neonatal medicine, the problem of course, is that it is difficult to determine in many cases whether the net benefit is positive or whether it is outweighed by the burdens. Frohock suggests that this determination is made easier for incompetent patients, such as infants, if two considerations are kept in mind: [34]

> The first is that some medical outcomes are clearly primary goods, meaning that they are valuable in themselves and desirable to virtually all rational individuals. Health is such a good. (Life may be a conditional good - desirable only on the satisfaction of other conditions, among which may be certain levels of health. That patients want a restoration of health can be assumed without reconstructing the preferences of the individuals to be treated (though if the therapy is particularly painful or hazardous, some consideration of preferences may be needed). Health, on the whole, is an assumed goal of medical practice, capable of being overridden by other considerations but justified as a desirable end state in the absence of

> overriding considerations. Since infant children cannot provide such countervailing arguments, cannot consider subordinating health to other goals, the primary goal of medicine in restoring health is more firmly fixed in the nursery than in treating competent adults.
>
> The second consideration is the form of life about which harm is to be determined. Life without a nervous system cannot be harmed by means of physical pain ... On the same logic, a life incapable of conscious experiencing cannot suffer the same deprivation of a life without the possibility of consciousness. An anencephalic baby is not deprived of sentient life when treatment is withheld. An embryo in vitro is denied the future possibility if conscious life is destroyed. In each case the form of life provides the range of harms that are possible.

This analysis of the concepts of benefits and burdens suggests that in balancing the benefits and burdens of proposed medical treatment, little or no benefit should be ascribed to continued life for an infant who has no capacity for conscious existence. Nor is a net benefit to the patient perceived when the infant's existence will be marked by irremediable pain and suffering without the possibility of restoration to a state of health.

Nonetheless, it can be argued that this concept of harm which is based solely upon the child's medical burdens is too narrow. These infants may also suffer from nonmedical or social burdens, such as poverty, parental rejection and abandonment, parents who are ill-equipped to provide care, and possible institutionalization. [35] In balancing the possible harms to an infant, these "socially-caused burdens" when added to the infant's "medical disabilities" may cause a decisionmaker to conclude that death would be in the infant's best interest. This argument has a certain merit as John Arras points out: [36]

> So long as burdensomeness to the child remains the crucial criterion involved in the best interest standard, why shouldn't social as well as purely medical burdens count in our overall calculations of best interest? ... The important thing it might be said, is not the source of the burden, but its effect on the child.

The problem with considering nonmedical burdens is that it is contrary to the principle of justice which requires that 'similar cases to be treated similarly'. Medical care should be given on the basis of medical need. [37] All infants who would benefit from medical treatment should be given equal access to such treatments. To deny treatment to one child, while giving it to another with the same condition, merely because the former is born into a poor family or has parents who reject or abandon it, is to visit a further injustice on that child. Arras concludes:[38]

> The procedural implication of this argument about justice is that we should attempt to distinguish clearly between "treatment decisions" and decisions regarding the child's ultimate disposition.

Thus, treatment decisions should be based solely on the infant's medical condition. This does not deny the moral dilemmas tht physicians find themselves in when they are faced with providing treatment to an infant with adverse social burdens. Arras describes these situations as a "moral blind alley" as whatever choice is made results in doing something morally unacceptable. However, he correctly submits that the principle of justice must prevail and that the answer lies in seeking increased societal support for programs to assist the handicapped not in unfairly denying lifesaving medical treatment to certain handicapped infants.[39]

2. Whose View Shall Govern?

Should the perspective of the competent adult or that of the defective infant be the standard by which the harms and benefits of the infant's continued existence are to be assessed?

Both perspectives have been employed by the courts in deciding whether medical treatments should be given or withheld from incompetent patients - through the "best interests" test and the "substituted judgment" test.

(a) Best Interests Standard

This standard requires an objective assessment as to whether or not the proposed medical treatment will on balance benefit or harm the incompetent patient. If most reasonable persons would conclude that they would prefer death to continued life under the circumstances, then treatment may be withheld or withdrawn.

Proponents of the "best interests" test argue that this is the only logical approach to making decisions for incompetent infants, since it is impossible to apply a subjective infant oriented standard for two reasons. First, a newborn infant can have no preferences. The infant has no past history of choices nor has he developed a subjective consciousness from which he can form desires or wishes. Thus, they argue it is impossible to don the infant's "mental mantle" and guess what he would choose if he were lucid for a moment. [40] The second reason for rejecting the substituted judgment doctrine is "that no one - especially normal, healthy adults - can 'place' themselves in a defective newborn's position and view life from that perspective." [41]

(b) Substituted Judgment Test

In applying the "substituted judgment" test the decisionmaker attempts to make the decision the incompetent person would make for himself if he were competent, based upon the incompetent's own values and interests.

Those who advocate the use of an infant oriented perspective as the standard by which the infant's burdens are to be measured cite two principal arguments against the use of the "best interests" test or "reasonable person" standard in decisionmaking for defective infants. [42] The first objection concerns the possibility of abuse, since the reasonable person standard "leaves the child unprotected against the whims and vagaries of normal adults." [43] The second objection is against the reasonable person standard itself, not its misuse. John Robertson suggests that the problem is that, any standard which is based upon the capacities and experiences of normal adults is bound to be prejudicial to the interests of defective children.[44] This view is echoed by John Arras who writes:[45]

> Why should the sentiments of normal adults be used as the touchstone of meaningful life for defective newborns? Although most normal adults are no doubt well-meaning and genuinely concerned not to abuse their standard of judgment, they are undoubtedly biased in favor of normalcy ... Having grown accustomed to the social and intellectual satisfactions that normalcy makes possible, it is only natural to expect that, were the question put to them, many normal adults would rather die than live without these normal human capacities.

Arras concludes that the standard of the reasonable adult, which is grounded on normal capacities cannot help but introduce a "systematic bias" into the decisionmaker's considerations. The central question which must be asked, in his view is,[46]

> not whether a normal adult would rather die than suffer from severe mental and physical impairments, but rather whether this defective child, this child who has never known the

> satisfactions and aspirations of the normal world, would prefer nothing to what he or she has.

This approach was adopted by MacKenzie, J. in the Dawson case. He declared that, "[i]t is not appropriate for an external decisionmaker to apply his standards of what constitutes a liveable life and exercise the right to impose death if that standard is not met in his estimation." [47] The proper standard, according to MacKenzie is from the perspective of the disabled child.

However, the Supreme Court of Canada rejected the "substituted judgment" test in Re Eve. The Court stated: [48]

> But it is obviously fiction to suggest that a decision so made is that of the mental incompetent, however much the court may try to put inself in her place. What the incompetent would do if she or he could make the choice is simply a matter of speculation.

Each of the above standards has appealing features. The reasonable person standard makes particular sense when applied to an infant who does not have any capacity to have any preferences or desires. It clearly requires great effort on the part of adults to even begin to imagine what such a child's preferences would be and may well be "impossible" as proponents of the reasonable person standard suggest. However, to fail to at least try to imagine what that child's life would be like from its own perspective seems to avoid the central issue which is, would this child prefer death to the life which he has before him. There is no doubt that in the majority of cases, in which decisions must be made regarding the treatment/nontreatment of defective infants, that the application of either test would lead to a similar decision being made. However, in a few instances, an attempt to consider life from the child's viewpoint may result in a decision to provide treatment that would not be made using the purely objective "best interests" test.

The substituted judgment test as envisaged by the President's Commission seems to provide the best method that proxy decisionmakers have of making decisions in best interests of anomalous infants. The Commission concluded that a "very restrictive" standard is appropriate in determining the best interests of an infant and stated: [49]

> Though inevitably somewhat subjective and imprecise in actual application, the concept of "benefit" excludes honoring idiosyncratic views that might be allowed if a person were deciding about his or her own treatment. Rather, net benefit is absent only if the burdens imposed on the patient by

> the disability or its treatment would lead a competent decisionmaker to choose to forego treatment. As in all surrogate decisionmaking, the surrogate is obligated to _try_ to evaluate benefits and burdens from the infant's own perspective. (underline added).

If this approach were followed the decisionmaker would first consider the factors involved that would move a competent or rational decisionmaker to forego treatment and following that determination, would then attempt to weigh and balance the harms and benefits of the proposed treatment from the perspective of the defective child. It would avoid the bias of normalcy inherent in the best interests test yet it would also avoid the purely speculative subjective approach of the substituted judgment standard by requiring an objective basis for the decision.

B. Application of Ethical Guidelines

(1) Selection by Categories

An application of the principles of beneficence and nonmaleficence to the kinds of cases which arise in neonatal practice leads to the conclusion that there are certain rare congenital anomalies and conditions which are so devastating that continued life cannot reasonably be said to be in a child's best interests.

In some cases the infant may be born in the process of dying and no available treatments can reverse the process. Alternatively, the child may suffer from a condition which is ultimately terminal (though not immediately) for which medical treatment can only prolong life at the cost of inflicting or promoting continued suffering. It is in these types of cases that medical treatment may justifiably be withheld or withdrawn.

An application of the principle of justice in medical care, as stated earlier, requires that 'like cases be treated alike'. This means that when selecting infants for nontreatment defective infants should not be compared with 'normal' infants nor should they be compared with infants with other types of disabilities. Rather, all infants should be placed in categories, i.e., all anencephalic infants, where possible, and policies regarding the provision or withholding of treatment should be determined according to particular categories. Justice would be served, since treatment would be provided on the

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basis of medical need and the policy would promote equality, since all infants within each category would be given the same treatment.

Defining specific categories or conditions for which treatment may be withheld or should always be given will not eliminate the problem of uncertainty in neonatal medicine. However, as a first step it can serve to "reduce the range of uncertainty."[50]

Within neonatal practice, cases can be divided into three categories. First, there are cases (the majority) in which treatment is clearly beneficial and should be provided. Second are those cases in which treatment can offer no benefit and should be withheld. Third, are the cases in which the benefits of treatment are uncertain, and in which the answer is unclear.[51]

The first step in categorizing cases presents few problems. Disagreements arise however, in attempting to determine which conditions should be included within each of the three categories and the reasons for doing so. However, in the extreme cases there is substantial agreement. Virtually all commentators agree that anencephalic infants belong in the second category (withhold treatment) since treatment is futile. Similarly, all would agree that a normal infant with a duodenal atresia belongs in the first category (treatment required) and should be treated.

The major difficulty in attempting to set up a classification system setting out specific criteria and conditions is "the almost limitless and unpredictable complexity of individual cases." [52] Another important difficulty is the lack of medical consensus regarding treatment about many of these cases. However, there are a number of extremely severe conditions that physicians do agree on.

Robert Weir, who has thus far made one of the few attempts to systematically identify a number of congenital conditions that represent a fate worse than death, points out that this method of selection is useful as a "primary" method of selecting infants for nontreatment. In other words, selection by diagnostic categories is applicable for category one (always treat) and category two (do not treat). However he suggests that a secondary method of selection is necessary for cases which are uncertain (category three).

While many commentators agree with selecting by diagnostic categories, few have actually discussed the conditions they believe would automatically merit treatment or nontreatment. This is typified by Robertson and Fost who write: [53]

> What is needed, then, is either a set of authoritative criteria describing the limited circumstances in which ordinary care may be withheld from defective newborn infants, or a process of decision-making which minimizes the risk of abuses or mistakes. We do not here attempt to articulate those criteria, other than to point out that if nontreatment is ever justified, it is because the nature of the defect, developmental potential, cost to parents and society, etc. seems overwhelmingly to argue against nontreatment.

The lack of stated criteria on the part of physicians may be due to the fact that physicians writing in this area assume that other physicians know the conditions and the criteria they are referring to. Doctors Alexander Cambell and Raymond Duff make this comment in their "Response" to ethicist Richard Sherlock's criticism of their apparent "unwillingness" to state criteria which would distinguish infants who should be treated from those from whom treatment could be withheld. [54] Cambell and Duff state: [55]

> Most doctors will know what we mean but we accept that some clarification may be necessary for non-medical readers.

This stated, they then list a number of severe conditions in which they would consider withholding life saving treatment. For Cambell and Duff, the criterion of central importance is damage to the nervous system, particularly the brain. They submit that treatment should be withheld or withdrawn in the following cases: [56]

> anencephaly; hydranencephaly; extreme forms of hydrocephalus especially if complicated by other abnormalities or by CNS infection, and certain chromosome disorders such as trisonomy 13. Infants with fully documented severe brain damage following asphyxia, hemorrhage or infection might also be included in this category. At the present time 'heroic' life-sustaining treatment also seems equally pointless in children with progressive degenerative disease of the brain such as leukodystrophies; or in the terminal stages of intercranial cancer.

Ethicist, Robert Weir has divided infants from whom treatment should be withheld into two groups. The first group consists of infants with lethal conditions for which treatment is futile since there is nothing that can currently be done for these infants. Weir describes withholding treatment in these cases as "desisting unsuccessful rescue." Included in this group are infants with: [57]

> anencephaly; other untreatable neurological conditions (e.g. craniorachischisis totalis, myeloschisis, massive suborachnoid hemorrhage, Chiari II malformation); infantile polycystic kidney disease; untreatable types of congenital heart disease (e.g., hypoplastic left ventricle); and multiple severe anomalies requiring repetitious efforts at resuscitation.

Infants in Weir's second group differ from those in the first group in that their lives can be prolonged through aggressive treatment. In these cases treatment should be withheld and these infants "allowed to die" since continued treatment will, in Weir's view, "subject them to a fate worse than death." These conditions are: [58]

> hydranencephaly; trisonomy 18; trisonomy 13; Lesch-Nyhan syndrome; Tay-Sachs disease; lissencephaly; cri-du-chat syndrome; and metachromatic leukodystrophyy.

In balancing the harms and benefits associated with the treatment of these conditions Weir provides four reasons for concluding that death is preferable to continued life for such infants. First, most of the infants suffering from these conditions will have an "extremely short life expectancy", with the majority dying within one year even if treatment is given. Second, at present "no curative or corrective treatment" is available for children with these conditions. These infants will ultimately suffer from severe and progressive physical and neurological deterioration that physicians are powerless to stop. Third, any of these infants who survive for any length of time suffer from "serious neurological deficiencies", generally with I.Q.'s ranging from less than 50 to below 25. Fourth, in addition to the neurological deficiencies suffered there are a "multiplicity of other serious problems", that are associated with these conditions, such as apnea, hypotoria, seizures and numerous others specific to the particular conditions.[59] In view of the terrible features of these conditions and the lack of 'effective' treatments, Weir argues that continued life for these infants represents a fate worse than death and therefore that treatment may justifiably be withheld.

A similar classification system has been proposed by a legal commentator, Larry Gostin. Gostin classifies defective infants into three categories in which selective nontreatment decisions can be made.

Category one includes infants who are permanently comatose and there is little likelihood that they will return to a cognitive, sapient state, as in the Quinlan case. Conditions fitting this criteria are "anencephaly, hydranencephaly and extreme forms of hydrocephalus." [60] Category two includes infants whose potential for dealing with, and responding to, sensory information and experiencing thought is de minimus. Included within this category, according to Gostin, are infants, [61]

> born with a progressive, degenerative disease of the brain such as infantile leucodystrophy, with certain severe chromosome disorders such as Trisonomy 13, with gross and imminently life threatening abnormalities such as the total absence of kidneys, and with fully documented brain damage following asphyxia, hemorrhage or infection.

Gostin suggests that the prospect of continued existence may be even worse for these infants than those in the first group, since they may experience pain and discomfort, while those in the first group cannot.

Category three includes infants who are terminally ill and in the process of dying. For Gostin, dying need not be imminent in a matter of days or weeks but must be "unavoidable within months or several years at the most." Terminal illness is the primary justification for nontreatment in this category however Gostin points out that it is not by itself a sufficient justification for authorizing nontreatment. He therefore proposes a list of additional relevant criteria which include: [62]

(a) severe or progressively increasing pain and suffering;

(b) severely impaired cognitive and learning potential which precludes social or human interaction;

(c) multiple physical disabilities preventing any significant voluntary movement; and

(d) multiple severe impairments or absence of sense perception, particularly sight and hearing.

If there is "clear medical evidence" attesting to the presence of all or most of these criteria then, he concludes, a nontreatment decision is warranted. If the medical evidence is contrary or inconclusive, treatment should be given.

While admitting that the parameters delineating this category are less clear than are those of the first two categories, Gostin believes that by employing a "balancing process", done on a "case by case basis" it is possible to determine which infants would fall within this category. He points out that each of the above criteria is "an important part of the balance and objective medical evidence on each factor should be sought."[63] Infants with Tay Sachs disease or Menkes Syndrome or Trisonomy 18 would fall within this category. However, Gostin expressly points out that infants with Down's Syndrome or spina bifida would not be included in this category unless they also meet the additional criteria he proposed.

A review of the conditions proposed by the preceding commentators in which nontreatment would be justified illustrates that there is substantial agreement (at least among these four commentators) regarding the most serious and severe conditions. Thus, it is reasonable to suggest that guidelines specifying the types of conditions in which nontreatment is clearly warranted could be developed and applied uniformly by hospitals engaged in referring and treating seriously defective infants. Similar guidelines could be developed enumerating those conditions in which treatment should be given. Obviously, since this group would compromise the majority of cases within neonatal units it may not be possible to specifically enumerate all the conditions/anomalies in which treatment should be given. If a condition is not included within the withholding treatment category, there should be a presumption in favour of treatment unless the severity of a particular case militates against treatment being offered.

The benefits of selection for treatment/nontreatment by specified categories accrue to all of the parties involved. Most importantly, this approach would offer a greater degree of protection for infants against overtreatment as well as undertreatment. Infants suffering from specified devastating conditions would not be condemned to suffer from futile or aggressive treatments that could only prolong their suffering on the basis of parental demand or medical research interests. Similarly, infants suffering from minor defects would be offered treatment regardless of the idiosyncratic or capricious views of their parents or their physicians. Furthermore, such guidelines would eliminate unfair and poor quality nonmedical (paramedical data) information being used to deny some infants necessary and beneficial medical treatment.[64]

Prospective parents could be made aware of the existence of these conditions and treatment policies prior to birth (in prenatal classes and by obstetricians). Parents who subsequently had infants suffering from a condition in which treatment would be withheld would not then be faced with an agonizing decision that they might later feel guilty about, no matter what they decided, nor would they be pressured to allow medically useless treatment based on physician research interests.

Neonatologists and pediatric specialists would also benefit. There would be greater certainty within the medical community once guidelines enumerating treatment policies for specific conditions were developed. It would be easier for the individual physician to express to parents and to obtain their agreement regarding treatment or nontreatment of their infant when clearly articulated policies are in place, and these guidelines would minimize to some degree the legal uncertainty which presently exists regarding the required medical treatment of anomalous infants.

Although selection by specific categories would provide some needed clarity regarding treatment/nontreatment decisions in many cases, for other cases which do not fit within the specific categories and it is is not clear whether continued life is beneficial or harmful, another method of selection is necessary.

2. Decisionmaking in Borderline Cases

(a) The Distinction between "Ordinary" and "Extraordinary" Treatments

One suggested guide to decisionmaking in problematic cases which fall outside specific categories is provided by the traditional distinction between "ordinary" and "extraordinary" means of treatment. Those who use the distinction say that "ordinary" treatments are morally and legally required, whereas "extraordinary" treatments are considered to be morally optional.[65]

Robert Weir advocates the use of the distinction as a secondary, and more flexible method of making treatment decisions in cases which do not fit within specific diagnostic categories. However, he contends that the distinction is "inherently ambiguous" since the terms "ordinary" and "extraordinary" have assumed too many conflicting meanings to remain useful. Therefore, he suggests that "extraordinary/ordinary" be replaced by the terms "obligatory" and "optional". The obligatory/optional distinction would serve the same purpose as its predecessor, according to Weir, by[66]

> recognizing that some life-prolonging treatments are morally expendable for some patients, no matter how customary the treatments are in medical practice, because the treatments are judged to be nonbeneficial and possibly harmful on balance to the neonate whose life is at stake.

The distinction would provide the flexibility necessary for decisionmaking since it would focus on the unique factors of a particular case.

Using the obligatory/optional approach would allow the decisionmaker to withhold treatment in very severe cases of a condition or anomaly that would normally be treated, for example, a severe intraventricular hemorrhage.

The availability of medical technology would be a relevant factor with newer and more experimental treatments considered to be more optional. Likewise, the more severe an infant's condition, the more likely that treatment would be considered optional, since efforts at treatment would more likely be ineffective or harmful to the infant. [67]

Weir concludes by citing three guidelines which would assist the decisionmaker in determining when treatment could be considered to be optional rather than obligatory. He suggests that treatment may be considered optional in a particular case if (1) on balance, it is not beneficial to the infant, (2) when it is harmful to an infant, or (3) the functional ability of the infant's family is threatened. [68]

Weir's first two guidelines are in keeping with the best interests of the infant standard he espouses. However, this third guideline contradicts the best interests standard. Although Weir believes that it should count only in rare cases, he cannot make judgments that treatment is in an infant's best interest and at the same time consider the harm to the family and then decide that treatment should not be given.

Both the "ordinary/extraordinary" distinction and Weir's "obligatory/optional" distinction have been criticized. The Supreme Court of New Jersey rejected the distinction between "ordinary" and "extraordinary" treatment which they found "unpersuasive" for several reasons. One reason was the wide range of meanings attributed to the terms "ordinary" and "extraordinary". The court concluded that, "[d]epending on the definitions applied, a particular treatment for a given patient may be considered both ordinary and extraordinary." 69 Another reason was that rapidly changing medical technologies would lead to disagreements about whether a treatment should be considered ordinary or extraordinary.

A similar criticism of Weir's "obligatory/optional" distinction is made by ethicist, Thomas Murray who does not believe that it is much of an improvement over the "ordinary/extraordinary" distinction. Murray argues that 'obligatory' and 'optional' are expressions of "the conclusion rather than the basis of the judgment", and he submits that: 70

> Gliding over the reasons underlying the judgment gives the false impression of moral certitude to what are, at best, very difficult and often contestable judgments about the proportionality of ends and means.

In Murray's view, the concepts of 'benefit to the patient' and the question of 'which and whose burdens to count' have not yet been satisfactorily answered, and Weir's approach attempts to mask this fact. He suggests that it is preferable therefore to speak in terms of "the proportionality of effort expended to the benefit likely to be achieved." [71] The language of proportionality suggests that these are balancing judgments and does not ignore the fact that judgments about which benefits and what burdens shall count are being made.

(b) Bayes Theorem

Fred Frohock and Wesley Sokolosky have each suggested an approach to treatment based on Baye's theorem, in order to ensure that all relevant factors are considered prior to making treatment decisions. Frohock writes: [72]

> Bayesian decision-rules are the most appropriate rules to use in the conditions of uncertainty found in the nursery: here a rational decision combines expected value with probability to yield the best utility return.

This approach requires the decisionmaker to determine the alternative courses of action that are possible. Next, the risks and benefits, including the desirability and likelihood of each alternative are established and following this, the alternatives are then compared. Numerical values are assigned to the likelihood of an outcome or an event, and to the consequences which flow from the proposed treatment or nontreatment. 73 Frohock cites the following example to illustrate the application of the theorem.

> A patient must decide whether to accept or forego treatment in the following situation. With treatment he has a 5% chance of complete recovery with a 95% chance of an unconscious and marginally painful existence. Without treatment, death is virtually certain. The patient must assign a value to each of these outcomes. In the example, death is assigned a value of -5. A comatose existence is rated as a fate worse than death and is therefore assigned a value of -10, while recovery is assigned a value of 10. Expressed as a mathematical calculation the utility value of treatment appears as follows:
>
> $$\begin{aligned}1(-5) &\text{ vs. } .95\,(-10) + .05\,(10)\\ -5 &\text{ vs. } -9.5 + .5\\ -5 &\text{ is greater than } -9\end{aligned}$$
>
> The rational decision in this instance would be the option for treatment. 74

Alternatively, he suggests, a variant of the Bayesian rules could be adopted. This approach, known as the von Neumann-Morgenstern test, requires a comparison of "risk against expected value" which determines "a cardinal utility scale unique for individuals." [75] In this example, a patient must try to decide on treatment, given the following conditions. He has a chance for an intact life, _a_, an unconscious life, _b_, based on assigned probabilities, _p_ of _a_ versus _b_. The calculation is expressed as: $p(a) + (1-p)(b)$. A comparison is made between the product of this expression and the certainty of death, _c_, given various probabilities (p's). Forhock explains that, [76]

> [a] very high probability will incline the patient to choose therapy; for if the chances are very good that treatment will be successful, any rational person will decide to be treated.

As the value of p is reduced the probability of success diminishes until a point is reached where $p(a) + (1-p)(b) = c$. At this point, there is no advantage to be gained by treatment, and therefore it is of no consequence to the individual whether or not it is given. [77] A probability value below the equilibrium point means that death is preferred and therefore no treatment is chosen.

Each of these methods can enable the decisionmaker to make rational choices. However, there is a danger in employing a mathematical model as a method of decisionmaking as it may lead to the erroneous assumption that "rational" choices are the same as "right" choices. This assumption masks the fact that the decisionmaker arbitrarily assigns values to life, death and unconsiousness. Different individuals may well assign different values to these states and any other alternatives and therefore different rational choices will be disclosed by the calculations.

Thus, the same criticism that was leveled at the "extraordinary/ordinary" and "obligatory/optional" distinctions can be made about these formulas which is that they express conclusions rather than the basis of the judgments that are made using them. [78]

Another problem which both the "obligatory/optional" approach and the Bayes theorem methodology fail to address is that there will always be uncertainty or ambiguity in certain cases which no formulas or standards can eliminate. Nor can the application of ethical principles (beneficence, nonmaleficence, justice) transform choices regarding treatment/nontreatment into a precise science. [79] All that can be done is to provide a range within which the decisionmaker may exercise his or her legitimate discretion. Ambiguous cases in which no discernible benefit is seen in providing treatment will require the decisionmaker to choose the infant's best interest since discovery of the infant's best interest may not be possible.

(c) Suggested Approach for Difficult Cases

Once it is determined that the infant's case falls outside the (1) Do not treat and (2) the Always treat categories, the decisionmaker(s) must try to assess as best as he or she can the probable harms and benefits of proposed therapies. The greater the uncertainty there is about whether treatment or nontreatment would be in the infant's best interests the greater should be the hesitancy to reach a quick decision opting for nontreatment. In many of these types of cases a decision does not have to be made right away. "Rarely is truly emergency treatment required. Much can be done to temporize." [80] Efforts should be made to stabilize the infant until more is known.

If, after weighing the probable harms versus the potential benefits of treatment it is unclear whether treatment is in the best interests of the child then two possibilities suggest themselves. The first is that a presumption in favour of life should be assumed and treatment should be given, or alternatively, to let the decisionmaker exercise his or her discretion and decide. The latter approach appears to be the best alternative if the decision is carefully and thoughtfully made following the ethical guidelines suggested above (based on the best interests of the child) and if a system or mechanism reviewing such decisions is adopted.

Possible mechanisms of review will be discussed in the following Chapter.

CHAPTER 4 ENDNOTES

1. Thomas H. Murray, "Why Solutions Continue to Elude Us," (1985) 20 Soc Sci Med, 1104; Canadian law presumes that an infant is a person upon birth: See Criminal Code, R.S.C. 1970, c.C-34, as amended, s.206.

2. John A. Robertson, "Dilemma in Danville," (1981) 11 Hastings Cent Rep, 8.

3. E.S. MacMillan, "Birth-Defective Infants: A Standard for Non-Treatment Decisions," (1978) 30 Stan L Rev, 619.

4. See for example, Joseph Fletcher, "Situation Ethics," in Encyclopedia of Bioethics, ed. Warren T. Reich, vol.1 (New York: The Free Press, 1978), p.p. 421-24; Richard Brandt, "Defective Newborns and the Morality of Termination," in Infanticide and the Value of Life, ed. Marvin Kohl (Buffalo, N.Y.: Prometheus Books, 1978), p.p. 46-60; Anthony Shaw, "The Ethics of Proxy Consent," in Decisionmaking and the Defective Newborn, ed. Chester A. Swinyard (Springfield, Ill.: Charles C. Thomas, 1977), p.p. 589-597.

5. In re Stephen Dawson (1983) 3 W.W.R. 618 (B.C.S.C.) reversing (1983) 3 W.W.R. 597 (B.C. Prov. Ct.), 620.

6. Robert Weir, Selective Nontreatment of Handicapped Newborns Moral Dilemmas in Neonatal Medicine (New York and Oxford: Oxford University Press, 1984), p. 225.

7. Earl E. Shelp, Born to Die? Deciding the Fate of Critically Ill Newborns (New York: The Free Press, 1986), p.126.

8. Id., at 126.

9. Norman Fost, "Ethical Issues in the Treatment of Critically Ill Newborns," (1981) 10 Ped Ann, 17.

10. Joel E. Frader, "Selecting Neonatal Ethics," (1985) 20 Soc Sci Med, 1086.

11. Id., at 1086.

12. Id., at 1086.

13. While undoubtedly many legal and ethical commentators do ignore the emotions involved in neonatal decisionmaking, not all do. See for example, John Robertson, supra n.2 at 6. Robertson comments that a decision was made by the attending physician and the parents to withhold food and water from the siamese twins at a time of "maximum emotional stress" and suggests that the decision should have been delayed for that reason.

14. Supra n.10 at 1087.

15. John M. Hemphill and John M. Freeman, "Medical Aspects and Ethical Dilemmas," in Encyclopedia of Bioethics, ed. Warren T. Reich, vol.2 (New York: The Free Press, 1978), p.720. See for example, Rasa Gustatis and Ernle W.D. Young, A Time to be Born, A Time to Die (Reading, Mass.: Addison-Wesley, 1986), p.22, where the authors point out that before 1980 infants of 600 grams (1 lb., 5 oz.) hardly ever survived, so it is impossible to know how those surviving will do as they grow.

16. Supra n.9 at 17.

17. Supra n.6 at 229.

18. Hemphill and Freeman, supra n.15 at 721.

19. Gustatis and Young, supra n.15 at 22.

20. Id., at 23.

21. Id., at 23.

22. Supra n.9 at 17.

23. Supra n.6 at 199.

24. Id., at 199.

25. Id., at 237.

26. Id., at 205-06; John D. Arras, "Ethical Principles for the Care of Imperiled Newborns: Toward an Ethic of Ambiguity," in Which Babies Shall Live?, eds. Thomas H. Murray and Arthur L. Caplan (Clifton, N.J. Humana Press, 1985), p.p. 106-108.

27. *Supra* n.6 at 206.

28. Fred M. Frohock, *Special Care: Medical Decisions at the Beginning of Life* (Chicago: University of Chicago Press, 1986), p.205.

29. Id., at 205-06.

30. *Supra* n.6 at 202.

31. *Supra* n.28 at 206.

32. *Supra* n.6 at 202.

33. *Supra* n.28 at 206.

34. Id., at 208.

35. These factors are considered by neonatologists in deciding whether to offer treatment to infants in Canadian neonatal units according to Magnet and Kluge.

36. *Supra* n.26 at 110-11.

37. Albert R. Jonsen, "Justice and the Defective Newborn," in *Justice and Health Care*, ed. Earl E. Shelp (Dordrecht, Holland: D. Reidel Publishing Company, 1981), p.101; Paul Ramsey, *Ethics at the Edges of Life* (New Haven and London: Yale University Press, 1978), p.201.

38. *Supra* n.26 at 112.

39. Id. at 112.

40. *Superintendent of Belchertown State School et al. v. Joseph Saikewicz*, 370 N.E. (2d) 417 at 431.

41. *Supra* n.6 at 198-99.

42. *Supra* n.26 at 115.

43. Id., at 116.

44. John A. Robertson, "Substantive Criteria and Procedures in Withholding Care From Defective Newborns," in *The Law - Medicine Relation: A Philosophical Exploration*, eds. Stuart F. Spicker,

Joseph M. Healy and H. Tristram Engelhardt, Jr., vol.9 (Dordrecht, Holland: D. Reidel Publishing Company, 1981), p.218.

45. Supra n.26 at 116-17.

46. Id., at 117.

47. Supra n.5 at 620-21.

48. Re Eve (1986) 31 D.L.R. (4th) 1 at 35.

49. President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, Deciding to Forgo Life-Sustaining Treatment (Washington, D.C.: U.S. Government Printing Office, 1983), p.p. 218-19. For a similar view, see the dissenting opinion of Handler, J. in In re Conroy, 98 N.J. 321, 486 A. (2d) 1209 at 1250 (1985).

50. Supra n.2 at 8.

51. Supra n.49 at 217; Alan R. and Thomas H. Murray, "Ethics Committees for Infants Doe?" (1983) 13 Hastings Cent Rep, 9; Kenneth, Kipnis and M. Gailynn, "Non-Treatment Decisions for Severely Compromised Newborns," (1984) 95 Ethics, 100-01; Raymond S. Duff, "Counselling Families and Deciding Care of Severely Defective Children: A Way of Coping with Medical Vietnam," (1981) 67 Pediatr, 315.

52. J.A. Robertson and N. Fost, "Passive Euthanasia of Defective Newborn Infants: Legal Considerations," (1976) 88 J Pediatr, 888. See also Arthur F. Kohrman, "Selective Non-Treatment of Handicapped Newborns: A Critical Essay," (1985) 20 Soc Sci Med, 1095.

53. Robertson and Fost, supra n.52 at 888.

54. Richard Sherlock, "Selective Non-Treatment of Handicapped Newborns: A Critique" (1979) 5 J Med Ethics, 139. The article which Sherlock's criticism is directed to is: A.G.M. Cambell and R.S. Duff, "Deciding the Care of Severely Malformed or Dying Infants," (1979) 5 J Med Ethics, 65-67.

55. A.G.M. Cambell and R.S. Duff, "Author's Response to Richard Sherlock's Commentary," (1979) 5 J Med Ethics, 141.

56. Id., at 141.

57. Supra n.6 at 235.

58. Id. at 235.

59. Id. at 236-37.

60. Larry Gostin, "A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates," (1985) 2 Am J L Med, 42-43.

61. Id., at 44.

62. Id., at 45.

63. Id., at 45.

64. See Chapter One: The use of "paramedical" information was documented by Magnet and Kluge in their surveys of Canadian neonatal units.

65. See decision in Chapter Three at p.p. 251-258.

66. Supra n.6 at 213.

67. Id., at 214.

68. Id., at 214.

69. In re Conroy, 98 N.J. 321, 486 A. (2d) 1209 at 1235. (1985).

70. Murray, supra n.1 at 1105.

71. Id., at 1105.

72. Supra n.28 at 209.

73. Wesley Sokolosky, "The Sick Child and the Reluctant Parent - A Framework for Judicial Intervention," (1981) 20 J Fam L, 85-87.

74. Supra n.28 at 210.

75. Id., at 210.

76. Id. at 210.

77. Id., at 210. However Frohock points out that this equilibrium point will occur only if the patient ranks a b c, where an intact life is preferred but death is preferred to an unconscious life.

78. Both Frohock and Sokolosky are well aware of the shortcomings of Bayesian analysis. Sokolosky comments that the "difficulty of establishing a numerical probability or desirability for any given consequence of a medical treatment would limit its usefulness."

79. _Supra_ n.28 at 215.

80. _Supra_ n.10 at 1089.

Chapter Five: Procedural Issues

I. Introduction

The preceding chapters have focused on the substantive issues involved in the current debate over the selective non-treatment of defective infants, with the following conclusions being drawn: (1) There is a limited class of infants, who suffer from devastating conditions from whom life-saving treatment may be withheld, and (2) an attempt should be made to develop guidelines which would specify the circumstances in which life-sustaining medical treatment may be properly withheld.

For those cases which are not easily categorized, or which it is unclear whether treatment is in an infant's best interests, the procedural issues assume greater significance. Philosopher, John Arras writes: [1]

> It may well turn out that, when confronted by the hard case, our substantive principles will founder on ambiguity and uncertainty. At such a juncture we may not know what the 'right answer' is, and we shall then have to 'solve' the problem by giving someone leave to cut the Gordian knot.

Thus, the central procedural question is, who should decide? Should such decisions be left up to parents or physicians, or should hospital ethics committees or the courts be required to decide difficult cases?

Another procedural issue, concerns the decisionmaking process. Should there be a stipulated procedure for making such decisions or a review mechanism to ensure fairness and consistency in decisionmaking and to protect infants from possible conflicts of interest between the infant and the decisionmaker?

These questions will be addressed in the followng section of this paper, beginning with the question, who should decide?

II. Who Should Decide?

Two opposing positions are taken with respect to this issue. Fred Frohock, has characterized one as the "Impartial Spectator" model and the other as the "Affected-Interest" model.

He explains that the rationale which underlies the impartial-spectator approach is the belief that "decisions on medical therapy can be more rational, if supervised and perhaps even ma~~de by those~~ who are not vitally linked with the child." [2] On the other hand, those who subscribe to the affected-interest model believe that, [3]

> those most strongly affected by a decision, with special interests in the outcome, ought to have their opinions weigh more heavily. Affection and commitment not distance, are said to be the best guarantees that the interests of the individual will be respected.

The proponents of each of these approaches have differing views as to who should decide whether treatment may be withdrawn from a defective infant since the qualities that each believes an ideal decisionmaker should have are very different.

Robert Weir, who subscribes to the impartial-spectator model, submits that an 'ideal' decisionmaker should possess the following qualities in order to make responsible decisions in neonatal cases: (1) Relevant knowledge and information, (2) impartiality, (3) emotional stability, and (4) consistency. [4] Weir's characteristics are similar to the list of qualifications of an ideal decisionmaker enumerated by Dr. Norman Fost, which were discussed earlier in Chapter Three. [5]

Both Weir and Fost contend that no 'one' individual would possess all of the qualities they list, and that parents would be unlikely to have many of them. Weir, however, is not willing to exclude the parents as decisionmakers, (with certain exceptions), while Fost favors the use of hospital ethics committees as a possible alternative.

The strengths and weaknesses of each of the possible decisionmakers are examined in the following section.

A. Parents

As discussed in Chapter Two, parents have the legal right and responsibility to make decisions regarding medical treatment for their children. This right is not absolute however; it may be overridden when parents make decisions which are harmful to the life or health of their child.

Those who contend that parents should retain the right to make treatment decisions on behalf of their infants, maintain that it merely reflects the discretionary decisionmaking power that the state leaves to parents in other areas of their children's lives.[6] They point out that our legislation recognizes and upholds the importance of parental automony, presuming that parents will generally seek the best interests of their children. Alexander Capron explains the reasons which underlie this assumption:[7]

> There are any number of explanations for this societal allocation of authority: respect for the family and a desire to foster the diversity which it brings; the fitness of giving the power to decide to the same people who created the child and have the duty to support and protect him; the belief that a child cannot be much harmed by parental choices which fall within the range permitted by society and a willingness to bear the risks of harm this allocation entails or a belief that in most cases "harm" would be hard for society to distill and measure anyway; or simply that the conclusion that the administrative costs of giving authority to anyone but the parents outweigh the risks for children and for society unless the parents are shown to be unable to exercise their authority adequately.

Accordingly, parents should decide since they are the most likely to be morally committed to the welfare and best interests of the child, and they are the ones who will reap the greatest benefits and bear the greatest burdens whether the child lives or dies. [8]

Nevertheless, others argue that parents cannot and should not make these decisions at this stressful time in their lives. Parents, Paul and Marlys Bridge, commenting on their own experience, wrote: [9]

> While we sincerely appreciated the opportunity to be consulted, we wonder whether parents of defective newborns are ever in a position to determine what is best for their child because of their emotional state, lack of knowledge and information, and inherent conflicts of interest.

The objections cited by the Bridges are commonly raised by those who assert that parents should not be permitted to make decisions regarding the fate of their defective newborn infants. They argue that the birth of a defective child is a severe shock to parents who have been eagerly awaiting the birth of a normal 'perfect' baby. The mother may be exhausted after a difficult delivery and both parents may be frightened and upset about their child's future as well as their own. Furthermore, they may not have the relevant medical information or may lack the ability to comprehend the information even if it is given to them.

Many doctors believe that if these decisions are left up to the parents, they will later suffer from guilt and remorse no matter what they decide. Therefore, some physicians advocate shielding the parents, by making the decisions themselves.[10]

Not all physicians subscribe to this view. Alexander Cambell and Raymond Duff write:[11]

> Can families in the shock resulting from the birth of a defective child understand what faces them? Can they give truly 'informed consent' for treatment or withholding treatment? Some of our colleagues answer no to both questions. In our opinion, if families regardless of background are heard sympathetically and at length and are given information and answers to their questions in words they can understand, the problems of their children as well as the expected benefits and limits of any proposed care can be understood clearly in practically all instances. Parents are able to understand the implications of such things as chronic dyspnea,

> oxygen dependancy, incontinence, paralysis, contractures, sexual handicaps and mental retardation.

In a subsequent article, Duff rejected the notion that emotionally distraught parents are unable to assimilate the necessary information. He maintained that "[b]eing emotionally troubled does not make parents unintelligent nor does it prevent them from using the intelligence they have." [12]

Although he agreed that parents cannot assimilate and understand _all_ of the technical information involved, he argued this was unnecessary in order for them to make informed decisions, since even the experts do not understand all of the issues completely and they often disagree. Other commentators who share this view, stress that there is no empirical data to support the assumption that parents are incapable of decisionmaking. [13]

Those who contend that parents should not be permitted to make treatment decisions on behalf of their defective infants also cite the potential conflicts in interest between the parents and the child. Raising a handicapped child, particularly one with multiple physical or mental handicaps, imposes tremendous psychological, emotional and financial burdens on a family. Parents lifestyles may be drastically altered and siblings' lives may be adversely affected because of the time and effort the parents must expend on the handicapped child. They believe that it is unfair to such infants to leave life and death decisions in the hands of those persons whose lives may be adversely affected by the infant's continued existence.

Finally, they suggest that parental autonomy in neonatal decisionmaking should be limited since there will be no consistency among cases. Decisions will be made on "irrelevant grounds" resulting in premature withdrawal of treatment in some cases and excessive or unwarranted treatment being given in others. [14]

B. Physicians

An alternative decisionmaker in neonatal cases is the neonatologist or the neonatal team who are responsible for providing care to the infant. Many doctors report that while they consult with the parents about their infant's treatment, they make the decisions themselves. In some cases, decisions are made unilaterally in order to protect infants' best interests when parents are incapable or unwilling to do so, while in others, physicians make the decisions for paternalistic reasons -- to protect the parents from anxiety or guilt which they might feel if they were required to participate in making these decisions.[15]

Some physicians, such as John Freeman, believe that the physician is "the only person capable of understanding the consequences of the decision,"[16] since he claims that it is impossible for the parents to make an informed decision given the short period of time in which decisions must often be made.

Other doctors contend that the decision will ultimately be the physicians's anyway, since the parents will be influenced by the physician's opinion.[17] Physicians have the specialized technical knowledge about the various congenital abnormalities and conditions and are in the best position to weigh and balance the harms versus the benefits of the various treatment alternatives. Furthermore, they are more likely to be able to make objective assessments than are the parents who are emotionally involved.

It is also suggested that physicians should make these decisions because there is less likelihood of a conflict between the infant's interests and the doctor's than there is between the infant and the parents. However, this is not always the case. Dr. Anthony Shaw describes situations in which a physician should not make the decision: [18]

> (1) When the infant's condition is one the physician is studying in a research program; (2) when he has a recognizable bias, especially if it is favor of human perfection; (3) when he is not qualified himself to fully evaluate the infant's condition or does not have ready access to such experts; (4) when he is unwilling to or fails to find ways of supporting decisions for life, that is, bringing in other experts in helping roles, especially from community agencies and services; or (5) when he conceals information from a parent in order to move them toward an objective of his own.

Shaw's examples illustrate that physicians' own interests may conflict with the interests of the infant in some cases. However, physicians' conflicts of interest are minimized when a medical team is responsible for decisionmaking rather than an individual physician. [19]

Other commentators argue that there is a greater chance for consistency in decisionmaking if doctors make the decisions since doctors base their decisions on accepted standards of medical practice and there is general agreement within the medical profession with respect to the most and least serious cases. Nevertheless, this is not always true because doctors may be swayed by external factors. For instance, physicians are often willing to comply with parental requests and thus may withhold treatment in accordance with the parents wishes although they would provide treatment in other similar cases.[20] Another reason cited for the lack of consistent decisionmaking by doctors is legal uncertainty. This was the conclusion reached by the Law Reform Commission in its working paper entitled, Euthanasia, Aiding Suicide and Cessation of Treatment. The Commission stated:[21]

> ... much of the variation in current practice can be explained by the uncertainty surrounding he state of the law. It is likely that excessive caution and continued use of aggressive measures are due far more to the fear of legal liability and prosecution than to the deliberate and intentional intrusion of the physician's personal attitudes and philosophies. We can reasonably conclude that the removal of these ambiguities and uncertainties will produce correspondingly greater uniformity in medical practice.

If the Commission's conclusion is correct, then until the "legal uncertainty" which surrounds neonatal decisionmaking is eliminated, there is no reason to believe that allowing physicians to make these decisions will lead to greater consistency in decisionmaking than if the decisions were left in the hands of the parents.

Finally, many ethicists reject the idea of physicians as decisionmakers since they maintain that decisions to withdraw treatment are moral decisions, which doctors are no more qualified to make than anyone else.[22]

C. Ethics Committees

Other commentators submit that neither parents nor physicians are suited to act as decisionmakers for defective infants due to conflicts of interest and emotional biases which may cloud their judgment.[23]

Two proponents of this view, John Robertson and Norman Fost, suggest that the legal concept of due process would protect infants from these potential conflicts of interest. They write:[24]

> The essence of due process is to maximize the probability that decisions will be made impartially after a full consideration of all relevant facts and

> interests, rather than on the uncontested perceptions and self-interest of one party.

In their view:

> A legal conception of due process would entail turning over decision-making to someone more likely to be disinterested than the parents or their private physician and assuring that the interests of the child are fully represented in that forum.

The forum could consist of "one or a group of physicians, a judge or a mixed lay and medical committee," [25] though Fost would favor a hospital ethics committee. Both Robertson and Fost submit that this process of decisionmaking would minimize the risk of abuse or mistakes.

A multidisciplinary committee would be more likely to consider all of the relevant issues and would have access to more information. Thus, there would be a greater chance for objectivity and impartiality in decisionmaking.

However, committees are not a perfect solution. Committees may not be able to respond quickly enough to make decisions in some cases and committee members may disagree. Thus, an alternative decisionmaker or procedure would have to be available.

Furthermore, parents and physicians who might be inclined to listen to the "advice" of a committee may resent a committee making the decision for them and thus may refuse to bring these cases to the committee's attention, unless committee notification is mandatory.

These aspects of committee use suggest that they may be more useful in an advisory capacity than as a primary decisionmaker in neonatal cases.

D. The Courts

Some legal commentators have suggested that the courts are the proper forum for making life and death decisions for incompetent patients. Charles Baron, a leading advocate of judicial decisionmaking, contends that the adversarial process offers the best protection of the patient's interest by ensuring "that the positions for or against treatment are equally as strenuously represented." 26

Baron believes that medical decisionmaking is unlikely to be impartial or consistent since "there are no institutional frameworks that require doctors to develop principles of decisionmaking that are consistent from one doctor to another and from one time to another." [27] Thus, he submits that decisions about similar cases may vary from day to day and from doctor to doctor. Moreover, doctors are often aware of "numerous prejudicial irrelevancies" about the patient which may affect their decisions making it less likely that the decisions will be impartial.

On the other hand, judicial decisions must follow established legal principles. These decisions are subject to review by appellate courts which ensures that the decisions are consistent with the law and past decisions. Therefore, he concludes, cases which are similar will be treated consistently.

Baron further argues that judicial process of decisionmaking emphasizes impartiality since only relevant factors or evidence may be considered by the court in reaching its decision.

Finally, Baron contrasts the "public nature" of judicial proceedings and decisionmaking with the process of medical decisionmaking which "goes on in the relative secrecy of intensive care units ... ."[28] He notes that judges must give reasons for their decisions but doctors need not. Thus, there is no opportunity for societal acceptance or rejection of what doctors are doing, as is the case with judicial decisions.

However, requiring the courts to determine whether treatment is to be given to or withdrawn for all incompetent patients would be impractical as well as unwise. In many cases, it would be an unwarranted interference in decisions that are within the medical profession's field of competence. Furthermore, the courts would be unable to cope with the sheer volume of cases they would be faced with. Incompetent patients would also suffer, since aggressive life-sustaining therapies would be given until a judicial determination could be made and their families would undergo additional strain because of the "public nature" of the proceedings.

For these reasons, the courts are an impractical alternative as the primary decisionmaker in the majority of cases involving incompetent patients. They have neither the expertise, nor the time to be involved in every case and should be regarded as a forum for resolving disputes in a few difficult cases.

E. Conclusions Regarding the Primary Decisionmaker in Neonatal Cases

Parents should retain the right to make medical treatment decisions for their seriously ill and defective infants. The majority of parents do attempt to base their decisions on the "best interests" of their children. The fact that a few parents do not is not a sufficient reason to remove decisionmaking authority from all parents. This same argument may be made against those who suggest that parents are incapable of understanding the complex medical information about their child's condition because of emotional distress or intellectual incapacity. Most parents are capable of understanding, if the information is presented in non-technical language, and if they are given time to understand and assimilate it.

For those few parents who cannot understand or who are unwilling to consider their infant's best interests, legal mechanisms are and should remain available to physicians to override parental decisions.

While physicians do have the technical knowledge that parents lack, they also have their own potential conflicts of interest and biases. Thus, they are not necessarily better decisionmakers than the infant's parents would be.

Both time constraints and costs involved militate against either hospital ethics committees or the courts being the primary decisionmaker in all cases. Although in a few cases, ethics committees and/or the courts may be useful and necessary.

What is clear is that there is no "ideal" decisionmaker for all cases. In the majority of cases, the parents are capable of making treatment decisions on behalf of their infants. Thus, there is no reason that the law should be changed to remove this authority from all parents since legal safeguards exist for usurping the parents' decisionmaking authority in appropriate cases.

To ensure that parents are being given adequate information and that decisions are based on valid criteria some mechanism of review is necessary, to ensure fairness and consistency in neonatal decisionmaking.

III. Reviewing the Decisionmaking Process

A number of different methods of review are possible which include: Legislative review; judicial review; internal administrative review; and ethics committee review.

A. Legislative Review

1. The Canadian Experience

There has been very little legislative supervision of the practice of neonatal medicine in Canada although in theory, Provincial Health Ministers have widespread powers over hospital administration and treatment.[30]

The closest involvement at the Ministerial level occurred in the wake of the infant deaths at the Hospital for Sick Children in Toronto. Special amendments were passed to the Ontario Public Hospitals Act which established a review committee [the "Dubin Committee"] to report on the quality of care and treatment of patients at the Sick Children's Hospital.

Ontario's Minister of Health forwarded the Dubin Committee's recommendations to each hospital with a neonatal unit. The hospitals were required to respond to the Committee's criticisms and recommendations and to indicate which recommendations would be implemented, which would not, and the reasons why. [32]

A second inquiry [the "Grange Commission"] was appointed by the Ontario government in order to determine the causes of death at the Hospital for Sick Children. The report of this inquiry was inconclusive and the Ontario government faced strong public demands to take decisive action against those responsible for the deaths and to prevent the occurrence of similar deaths in the future. [33] However, apart from the ill considered arrest of nurse Susan Nelles, no further charges were ever laid and there has been no further government regulation of Ontario's neonatal intensive care units.

2. The United States Experience

Six years ago, the United States government became actively involved in the neonatal decisionmaking process. The federal government's involvement was precipitated by the public outcry over an incident, which became known as the "Baby Doe" case. [34]

(a) The Baby Doe Case

On April 9, 1982, in Bloomington, Indiana, the parents of an infant born with Down's Syndrome and other defects [35] refused consent to permit surgery to remove an esophageal atresia which prevented the infant from normal feeding. The hospital initiated judicial proceedings to override the parents refusal. An emergency hearing was convened the night following the infant's birth. However, the hospital's petition was denied.

At the court's request, a review was conducted by the Local Child Protection Committee. The committee conducted its own hearing and concurred with the court's decision.

Another hearing was held on April 13, in which the court concluded that the infant had not been neglected under Indiana's Child in Need of Services Statute. The next day, the Indiana Court of Appeals denied a request for an immediate hearing. [36] Subsequently, the Indiana Supreme Court, by a 3-1 vote, rejected a petition for a writ of mandamus.[37] Six days after its birth the infant died, as one of the county prosecutors flew to Washington seeking an emergency stay of the Indiana court orders from the United States Supreme Court, which later denied certiorari.[38]

The case was widely reported and discussed in the media. Letters appeared in newspapers across the country condemning the parents decision and judicial inaction, and letters of protest were sent to both Congress and the White House demanding that action be taken to avoid further similar incidents.

(b) The Federal Government's Response

(i) Initial Response

On May 18, 1982, the Secretary of Health and Human Sciences (HHS), in response to a directive from the President, issued a "notice" to federally funded health care providers that Section 504 of the Rehabilitation Act of 1973 made it unlawful to withhold food or medical treatment from an infant who was handicapped. Section 504 provided, that[39]

> [no] otherwise qualified handicapped individual ... shall solely because of his handicap, be excluded from participation in, be denied benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance ... (emphasis added).

This notice was followed by an "Interim Final Rule" which required health care providers receiving federal funding to post "in a conspicuous place" in all delivery rooms, maternity and pediatric wards and NICU's, a notice that,[40]

> DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW.

The notice also encouraged anyone who had knowledge that a handicapped infant was being discriminated against by being denied food or "customary medical care" to contact the HHS or a State Child Protection Agency. A toll-free 24 hour hotline was set up and callers were guaranteed anonymity. Upon receipt of calls, HHS investigators would be dispatched to investigate the complaint and to protect the infant involved. The investigators were entitled access to all hospital records, and physicians, hospital staff and the infant's parents were required to be available for immediate questioning. The notice also stated that hospitals were in violation of section 504 if they allowed infants to remain in their care after the infant's parents or guardians had discriminatorily withheld their consent to food or medical treatment.

An action was brought by the American Academy of Pediatrics joined by the National Association of Hospitals seeking a declaration that the Interim Final Rule was invalid and an injunction against its enforcement. [41]

District Court Judge, Gerhard Gesell, invalidated the regulation, declaring it to be "arbitrary and capricious and promulgated in violation of the Administrative Procedure Act," since the Secretary had failed to consider "many highly relevant factors central to any appliction of section 504 to [the] medical care of infants" before enacting the challenged rule. These factors included: (1) the disruptive effects of a 24 hour hotline and the sudden descent of "Baby Doe" squads on the treatment of the infants, (2) the effects of causing the removal of a child from an institution if the parent refused to consent to treatment or the termination of funding to the hospital as a whole if the hospital permitted the infant to remain, (3) the advantages and disadvantages of allowing physicians to consider parents wishes in making treatment decisions, (4) whether termination of "painful and intrusive" treatment might be appropriate in some cases, (5) where funding was to come from to finance the "extensive care required by the regulation" and how "scarce medical resources" were to be allocated between defective infants and other patient groups, (6) what legal and constitutional considerations were considered, (7) what alternative means existed for protecting handicapped infants, and (8) what evidence there was to suggest that "a widespread denial of proper newborn care" existed that would justify the type of regulation selected." [43]

Further evidence of inadequate consideration by the Department in passing the regulation was evidenced by the text of the rule itself, which provided that the denial of "customary medical care" to defective infants constituted a violation of federal law. Judge Gesell noted that all of the evidence received by the Court (from both parties) had clearly shown that, "there is no customary standard of care for the treatment of severely defective infants," [44] which even the most cursory investigation by the Secretary would have revealed. He therefore concluded: [45]

> The regulation thus purports to set up an enforcement mechanism without defining the violation, and is virtually without meaning beyond its intrinsic *in terrorem* effect.

Alternatively, even if the rule had met the substantive requirements of the Administrative Procedure Act, it would have been invalid due to the Secretary's failure to comply with the procedural requirements of the Statute which required a brief period to solicit public comment before issuing the Rule.

(ii) The Revised Rules

On July 5, 1983, the Department issued new "Proposed Rules" intended to become effective after a 60 day comment period.[46] As did the Interim Final Rule, these rules also required the hotline notices but they were smaller and only had to be posted at nurses stations. However, the Proposed Rules now required state child protective services agencies to use their authority to prevent medical neglect of handicapped infants.

The Rules also clarified to some extent the circumstances in which they were to apply. A non-exhaustive list of conditions in which nontreatment would constitute a violation of section 504 was given.

They included decisions not to correct an intestinal or esophageal atresia in a Down's Syndrome child, unless additional complications were present that warranted a nontreatment decision, as well as cases of spina bifida with correctable physicial anomalies. The provision of sustenance, was "not an option for medical judgment," even where death was imminent or unavoidable, [47] although "futile therapies" that merely prolonged the dying of a terminally ill infant were not required. The purpose of these rules according to HHS, was to limit physician and parental discretion in making treatment decisions for infants based upon non-medical, subjective considerations about the probable quality of a child's life.

On October 11, 1983, an infant girl with multiple congenital defects known as "Baby Jane Doe" was born in Long Island, New York, and was transferred to University Hospital. After consulting with physicians and other advisors, the parents chose to forego corrective surgery that would likely prolong the infant's life but which could not correct nor improve many of her other handicapping conditions (severe retardation, paralysis, epilepsy and recurrent infections).

Right to life groups became aware of the parents' decision and within a few days a right to life attorney, who had never seen the infant or her parents, brought an action in the New York Supreme Court seeking an appointment of a guardian ad litem for the infant, who could consent to surgery since the hospital maintained that it would be willing to perform the surgery but not without the parent's consent.

The trial court appointed a guardian ad litem and ordered the surgery to be performed by a neurosurgeon associated with the hospital. [48]

The following day in a unanimous decision the appellate division of the Supreme Court reversed the decision of the trial judge. In its decision, the appellate court distinguished this case from the Baby Doe case stating that, [49]

> this is not a case where an infant is being deprived of medical treatment to achieve a quick and supposedly merciful death. Rather it is a situation where the parents have chosen one course of appropriate medical treatment over another. These concededly concerned and loving parents made an informed, intelligent and reasonable determination based upon and supported

> by responsible medical authority ... [We] find the parent's determination to be in the best interests of the infant.

This decision was affirmed by the New York Court of Appeals on the basis that there was no finding of neglect, and further, if a child was neglected, the state child welfare agency had the authority to petition the courts and not an individual with no relation whatsoever to the family. [50]

Prior to the final appellate court's decision, the HHS was notified by an anonymous caller that the infant was being denied medical treatment because of her handicaps. A complaint was filed by the HHS with the New York State Child Protective Service, alleging that the infant was being neglected. The agency investigated and found no cause to intervene in the case.

Meanwhile, the HHS repeatedly requested the hospital to permit it to inspect the infant's medical records in order to determine whether the hospital had complied with section 504. The hospital refused, since the parents had refused consent to release the infant's records.

Subsequently, the HHS filed suit in the Federal District Court alleging that the hospital had violated section 504 of the Rehabilitation Act and the new proposed rules and regulations adopted thereunder. [51]

The District Court ruled against the government, concluding that the hospital had not violated the statute, since the surgery had been withheld not because the child was handicapped, but because her parents had refused their consent. [52]

The government appealed to the United States Court of Appeals which affirmed the District Court's decision. It agreed that "an agency is not entitled to information sought in an investigation that 'overreaches the authority Congress as given'." [53]

The Court concluded that although Baby Jane Doe was a "handicapped individual" she was not "otherwise qualified" within the meaning of section 504 because "where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to the need for services," and thus "the 'otherwise qualified' criterion of section 504 [could] not meaningfully be applied to a treatment decision." [54]

Consequently, the infant was not "subject to discrimination" under section 504 since the handicapping condition was directly related to the condition to be treated and the Court reasoned, "[w]here the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was 'discriminatory'."[55]

An examination of the legislative history of section 504 as well as an examination of the practical difficulties encountered in attempting to apply section 504 to treatment decisions led the Court to conclude that Congress had never intended section 504 of the Rehabilitation Act to apply to medical treatment decisions for handicapped infants, and that unless Congress had so specified, the Court could not construe the Regulations enacted thereunder to apply to these decisions.[56] Thus, the government did not have the authority to gain access to Baby Jane Doe's medical records.

(iii) The Final Rules

On January 12, 1984, HHS issued proposed "final rules" to prevent discrimination of handicapped infants.[57] The rules encouraged hospitals to establish Infant

Review Care Committees (ethics committees) to assist hospitals in establishing policies and procedures in making treatment decisions in specified cases. The final rules also acknowledged that a hospital did not have a statutory obligation to provide treatment in the absence of parental consent, which the earlier rules had required.

These rules also required: (1) federally-funded hospitals to post notices that section 504 prohibited the withholding of food and medically beneficial treatment from infants solely on the basis of their handicap; (2) required state protective agencies to use their authority to prevent the medical neglect of such infants; (3) allowed HHS to have expedited access to the infants records, with or without the parents consent; and (4) allowed HHS to bring expedited compliance actions to enforce section 504 and to protect such infants.

The American Medical Association, the American Hospital Association, and others challenged the validity of the (4 requirements) Final Rules and sought to enjoin their enforcement. 58 Injunctive relief was granted by both the Federal District Court and the United States

Court of Appeals for the Second Circuit on the basis that section 504 did not authorize a direct federal regulatory role in such decisions.

The Supreme Court struck down the final rules, in part (the four mandatory requirements listed above) concluding that they were not authorized by section 504 as there was no evidence that there had been discrimination against handicapped infants in violation of section 504 since, [59]

> (a) HHS, while recognizing that a hospital's withholding of treatment from handicapped infants in the absence of parental consent is not discrimination on the basis of handicap, had justified the regulations on the basis of cases in which the parents refused consent;
>
> (b) although HHS had contended that hospitals might discriminate against handicapped infants by not reporting parents refusal to consent to treatment in such cases, there was no evidence that hospitals had in fact failed to report such cases, much less that they had done so because of the infant's handicap;
>
> (c) imposing an absolute obligation on state agencies to provide protective services to handicapped infants did not accord with section 504's focus on the relative treatment of the handicapped and non-handicapped; and
>
> (d) there was no indication that Congress, in enacting section 504, had

> intended to impose federal superintendence over a treatment decision process traditionally overseen by the states.

(iv) The Child Abuse Amendments

In the interim, Congress began considering an appropriate method of providing protection to handicapped infants. Rather than amending Section 504, Congress reviewed existing child abuse legislation and in September, 1984 Congress enacted amendments to the Child Abuse Prevention and Treatment Act of 1974 which established regulations governing the withholding of treatment from handicapped newborns.[60]

The amendments required the development and implementation of federally mandated procedures and programs (similar to the Baby Doe requirements) by state child protection agencies as a condition for receiving federal grants. These programs and procedures were designed to address possible cases of abuse in the form of medical neglect, which included withholding medically indicated treatment from infants with life threatening conditions. The programs had to provide prompt notification of cases of suspected medical neglect to state protection agencies and enforcement of the amendment requirements was also left to state agencies who had established authority to intervene in neglect cases. Federal involvement, including the hotline was eliminated.

The Child Abuse Amendments set forth a standard for determining medical neglect in neonatal care: [61]

> The term 'withholding of medically indicated treatment' means the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration and medication) which ... will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration or medication) to an infant when, in the treating physician's (or physicians') reasonable medical judgment any of the following circumstances apply:
>
> (i) The infant is chronically and irreversibly comatose;
>
> (ii) the provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
>
> (iii) the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. (Emphasis added).

The regulations further define "reasonable medical judgment" to mean "a medical judgment that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved." 62 By referring to "appropriate" nutrition, hydration and medication it suggests that where "reasonable medical judgment" concludes that nutrition, hydration and/or medication would be inappropriate, that it may be withdrawn.

The HHS's interpretive guidelines explain that "virtually futile" treatment is treatment which is "highly unlikely to prevent death in the near future," while "inhumane" treatment involves significant medical contradications and/or significant pain and suffering for the infant that clearly outweigh the very slight potential benefit of the treatment for an infant highly unlikely to survive." 63

The 1984 Amendments also recommended the establishment of hospital-based Infant Care Review Committees to provide counselling and information to parents in order to assist them in making decisions on the basis that such committees would ensure better decisionmaking and would "obviate the need for formal state legal proceedings against parents who must make these decisions." [64]

(c) Comments Regarding Legislative and Administrative Control Over Selective Nontreatment Decisions

The various federal legislative and policy responses to the Infant Doe case engendered considerable critical commentary.

Much of the criticism was levelled at the vagueness and lack of clarity of the provisions. Witnesses who testified before the President's Commission for the Study of Ethical Problems in Medicine "expressed concern that virtually every operative phrase of the DHHS directive need[ed] amplification and would be subject to varieties of interpretation." [65] Other writers criticized the regulations for offering no specific guidelines to neonatologists and others faced with actual decisions regarding the treatment given to handicapped infants. [66]

The legislation was also criticized for providing a simplistic solution to an extraordinarily complex problem since it was enacted to prevent the occurrence of any more Baby Doe cases. However, the legislation failed to consider the wide range of medical cases which occur in neonatal units and the varying levels of treatments that are available.

The implementation of the Baby Doe regulations was widely believed to have detrimental effects on the provision of neonatal care in the United States during the time they were in effect: (1) They created an adversarial atmosphere through the use of their coercive mechanisms; (2) divested parents of their rights to make treatment decisions for their children; (3) restricted doctors' discretion to make treatment decisions based on medical assessment of infants' best interests; (4) forced doctors to practice defensive medicine, resulting in the overtreatment and infliction of needless suffering on seriously ill infants; (5) the descent of Baby Doe squads was highly disruptive to hospital routines, causing doctors and nurses to expend valuable time answering investigative questions instead of caring for infants; and (6) forced hospitals into the role of policing physician and parental decisions.[67] Moreover, the perception arising from the imposition of the regulations was that medical professionals were child abusers who could not be trusted leading to public mistrust and lack of confidence in the medical profession as well as causing negative impact upon professional morale. [68]

Two questions have been asked regarding the intrusion of the government into the hospital nursery. First, was the legislation necessary? The HHS investigated 49 cases of alleged "discrimination" in the treatment of impaired newborns and by the Department's own account, in none of these cases was a "discriminatory" withholding of medical care found. [69]

The President's Commission had reached similar conclusions after conducting extensive hearings on the quality and kind of medical care being provided in the United States. Noting that tens of thousands of the more than three million infants who are born in the United States each year suffer from congenital defects and problems of prematurity which would result in early death if not treated, the Commission observed: [70]

> Yet it is rare for treatment not to be provided when it is predicted to provide a means of remedying the medical problem, the cases when approval for such treatment is denied are few enough to be noteworthy. While

> they are disturbing, they may be inevitable in a society that treasures personal and familial automony.

Furthermore, the Commission was leery of the notion that government intervention was the answer to these difficult cases: [71]

> Greater control by state officials, in the name of protecting the helpless, would actually be warranted only if it clearly saved more lives. Furthermore, such steps would raise problems of governmental intrusion into private matters, in many areas where no better decision can be made.

A second question is whether the governments' legislative responses constitute good policies. John Arras argues that they do not. While he admits that these policies "will dictate the morally correct result in many cases", and that President Reagan's "moral response to the Infant Doe case was ... perfectly appropriate", he contends that the issue "is whether the policy inspired by the Baby Doe case is good policy, not whether it was well-motivated, or even whether it will yield correct results in similar cases". [72] In his view, the government responses to the Infant Doe case constitute bad policy - for the very reason that they were "tailored to the Baby Doe case." He states: [73]

> Adequate social policy needs to be formulated on the broad understanding of moral and medical realities, not on moral outrage directed, no matter how appropriately, against a few highly publicized cases.

Although Arras believes legislation could be drafted to cover a wider array of congenital anomalies and conditions, as in the Child Abuse Amendment provisions, he argues, it is unlikely that any legislation can adequately cover the entire spectrum of cases which are found in neonatal nurseries. What is needed in the most difficult and complex cases is an individualistic approach with flexible guidelines that permits consideration of a variety of factors in making treatment decisions.

Another argument against adopting a legislative solution to the problem is that "legislatures will have difficulty taking into account the rapidly changing state of the art in neonatal medicine."[74] Solutions will be found for some current problems while new problems may arise. Moreover, it is argued that medical treatment for a seriously ill infant should be determined on the basis of carefully considered medical assessments and equally careful analysis of the moral issues involved. Treatment given merely in compliance with simplistic or vague legislation is not good medicine and may cause greater harm than benefit to some unfortunate infants, as well as placing increased pressures on parents who are already facing the most difficult decision(s) of their lives.

Even if such legislation is passed the enforcement mechanisms the government is able to implement are unlikely to be effective. Using investigative teams such as the Baby Doe squads would lead doctors and nurses to perceive themselves as being under attack and they would likely close ranks for self-protection. Thus, unless the government was willing to establish some type of ongoing surveillance program in every neonatal unit to ensure compliance with the law, it is unlikely that investigative squads would be very successful at rooting out prospective cases of abuse.

Furthermore, punishing hospitals through financial penalties when discriminatory practices occur is unfair because a reduction in funding penalizes the hospital, other patients, and health professionals who have no control over the actual treatment decision made by the parents and treating physicians.[75]

Nevertheless, some courts and academic writers have suggested that a legislature would be the best forum for resolving the issues raised by selective nontreatment. The Florida Supreme Court expressed this view when asked to order the termination of life-prolonging treatment for an elderly man, commenting: 76

> [b]ecause the issue [whether to sanction euthanasia by withdrawing or withholding treatment] with all its ramifications is fraught with complexity and encompasses the interests of the law, both civil and criminal, medical ethics and social morality, it is not one which is well-suited for resolution in any adversary judicial proceeding. It is the type issue [sic] which is more suitably addressed in the legislative forum, where fact finding can be less confined and the viewpoints of all interested institutions and disciplines can be presented and synthesized. In this manner only can the subject be dealt with comprehensively and the interests of all institutions and individuals be properly accommodated.

T.S. Ellis, an American attorney, writes that "[o]nly a legislative resolution promises that newborn treatment decisions will be, in some measure, consistent, predictable, adequately informed, and in accord with community values." Ellis believes that all of the relevant issues including the medical-technical, moral, and economic can be examined and reviewed in the legislative arena and ultimately a reasonable consensus can be reached.

However, it is submitted that this view fails to recognize that very little consensus has been reached on these issues within the medical and legal professions or among the philosophers and ethicists who have debated the issues, nor is there any widespread societal consensus thus far. While discussions and debate of these issues should be encouraged and may lead to a consensus evolving over time, the premature passage of legislation may hinder this process. On the whole, government regulation and review of treatment decisions is not the best mechanism for reviewing treatment decisions in neonatal units at the present time.

B. Judicial Review

1. Arguments in Favour of Judicial Review

Those who favor judicial review submit that parental decisions to withhold treatment from their children should be reviewed in order to ensure that proper decisionmaking procedures have been followed. They argue that the courts are the proper vehicle for assessing and weighing the conflicting interests involved in such decisions. One proponent of this view, Larry Gostin, writes:[78]

> Where there are societal, as opposed to purely clinical issues to be determined, it is for the courts to lay down general principles to be applied by the health care profession. The question of whether a treatment is indicated is a matter for the medical profession; whether a medically indicated treatment is to be withheld is a social/ethical matter for resolution in the courts.

Gostin believes that the courts should attempt to "develop clear and objective principles" which can then be left to the medical profession to implement. He points out that the courts have already done so in other areas of medical practice in the treatment of irreversibly comatose patients as well as policies concerning brain death. [79] For example, in the Conroy and Quinlan cases, the courts devised procedures which could be followed by physicians and families in making nontreatment decisions for such patients without requiring recourse to the courts.

However, there are in Gostin's view, two circumstances in which judicial review is warranted prior to effecting a decision to withhold treatment: [80]

> (1) Where there is a conflict of evidence or views which requires independent resolution, e.g., where there is no clear medical consensus as to the prognosis or there is disagreement between the

> patient or the patient's guardian and health care personnel on the appropriateness of treatment;
>
> (2) Where there is a conflict over the application of accepted legal principles. Where the facts fit clearly within objective criteria previously laid down by a court, prior judicial review is not warranted. The courts are only beginning to develop the broad concept of "best interests" into narrow standards which can be objectively applied to diverse factual situations. Therefore, the ideal scenario in which the facts can be fully squared with judicial precedent will not soon occur in relation to many situations of death and dying ...

An argument in favour of a more restricted scope of judicial review is made by another legal commentator, E.S. MacMillan. MacMillan contends that parents are the proper decisionmakers, who have the right to make treatment decisions on behalf of their children within reasonable boundaries free from interference by the State. She therefore suggests that courts should limit their involvement in reviewing the decisionmaking process to "no more than is necessary to protect the infant's interests". Thus, judicial review, in MacMillan's view, should be restricted to determining two issues:[81]

> First, the court will determine whether treatment of the infant's condition is infeasible (i.e., imminent death and

> irreversible unconsciousness). In order to affirm a non-treatment decision, the court must find clear and convincing evidence that the child falls within one of these two categories;
>
> Second, the court will determine whether proper decisional roles were followed. In order to affirm a nontreatment decision, the court must find that the physician made the medical prognosis, that the parents understood their options and that the parents made the final decision to withdraw treatment.

Differences Between the Two Approaches

If an infant is "irreversibly comatose" or suffers from "a severely impaired response potential" and the physicians and parents are in agreement about the treatment/nontreatment decision, Gostin sees no need for judicial review of such decisions. MacMillan, on the other hand, sees the need for judicial review in order to determine whether the infant is "irreversibly unconscious" or "faces imminent death". If the court finds on review that the infant does not meet either condition, the court cannot approve a decision to withhold treatment even if parents and physicians agree that treatment should be withheld. Gostin would permit the courts to consider other criteria in determining whether treatment should be withheld and the courts themselves should determine what the substantive criteria will be.

MacMillan would also limit the courts review to assessing whether the proper decisionmaking procedure was followed. If so, and if the medical conditions were met, the courts would defer to the parents' decision. For Gostin, judicial review requires the courts to arbitrate disputes between the primary decisionmakers with the courts making the decision themselves, based upon their own review.

2. Arguments Against Judicial Review

The major arguments against judicial review of neonatal decisionmaking are that the courts are costly, cumbersome and are often unable to respond quickly enough in life threatening emergencies. Dr. Marianne Prout, who testified before the President's Commission, compared the 'timing aspect' of medical decisions with that of legal decisions:[82]

> I ... think we have ... a real contrast in time-frame analysis between the medical and legal professions ... When

> we talk about quick court decisions we are talking about 12 days. When I talk about quick, it means running down the stairs rather than taking an elevator ... You have to understand when physicians want an answer they want it in 10 minutes. When lawyers produce an answer, they congratulate themselves for producing it in 10 days.

A number of cases brought before the courts have resulted in the patient's death prior to the court's reaching a decision. For example, in Eichner v. Dillon, the lower court took nearly two years to decide the case. However, the patient died of congestive heart failure one year before the issuance of the court's decision despite the maintenance of respirator support. [83] Similar results occured in the Saikewicz case, where Mr. Saikewicz died of leukemia prior to the appeal court rendering its verdict on whether he should be given chemotherapy. [84]

Other commentators question whether legal proceedings can ever adequately supervise medical practices since the process of medical decisionmaking differs greatly from the process used to reach legal decisions. Fred Frohock, a political science professor, who spent four months observing medical decisionmaking in a neonatal intensive care unit, analyzed the different approaches of the two disciplines and contrasted the two. Discussing medical decisionmaking practices, he writes: [85]

> Therapy decisions are serious and remedial. They proceed stepwise with frequent incremental revisions as information is updated. There are few final decisions in neonatology. Even decisions not to treat are reversible if conditions warrant. Therapy decisions in the nursery are also tentative, based upon imperfect information ... Therapy decisions are always part of a continual process of monitoring patients and revising judgments.

On the other hand, he describes legal decisionmaking in the following manner: [86]

> Legal decisions, especially those that culminate a legal proceeding, are singular and decisive. ... But nothing in the nursery parallels the finding or verdict at the end of a hearing or trial. Such decisions close inquiries. Law admits continuations of course. Decisions can be appealed ... and some decisions establish a series of decisions ... But the decision by a jury or judge can also decisively conclude legal activities (akin, one supposes, to a death in medicine).

Within neonatology, as is the case in other areas of medical practice, cooperation is essential. Medical practitioners regularly consult with one another and decisions are often made on the basis of a shared consensus. The adversarial approach employed in judicial proceedings is completely foreign to medical experience and physicians often believe it is antithetical to good medical practice. This view has been forcefully expressed by John Havard, Secretary of the British Medical Association, in an article discussing the prosecution of Dr. Arthur for the attempted murder of an infant suffering from Down's Syndrome by denying it food and medical treatment. [87] Noting that the Director of Public Prosecutions (DPP) had not disclosed whether the decision to prosecute Dr. Arthur had been based upon any medical advice and that Dr. Arthur's actions appeared to follow "accepted medical practice", he suggested that the prosecution had proceeded without adequate medical consultation. As a result, the attempt to ascertain the medical facts was left to the dubious processes of the legal system of which he writes: [88]

> The medical issues were therefore left to be determined under our adversary or accusatorial system in a criminal court of law ... Part of this game (and it is not for nothing that continental lawyers refer to the English 'sporting theory of justice') is to take the other side by surprise. Accordingly, the lawyers told Dr. Emery (the main expert for the defence in the Arthur case) that he was on no account to talk to Professor Usher (who appeared for the prosecution) before he had given his evidence at the trial. I find it surprising that the authors of the first paper ignored this fact. [He is referring to the legal commentary on the decision which preceded his own article]. Whereas it may be explained to the satisfaction of lawyers, it is

> beyond explanation in terms of any established scientific discipline. It would be difficult to devise a system less likely to arrive at the truth.

3. Response to Arguments Against Judicial Review

(1) Courts are too slow argument

Dr. Prout's remarks have some merit since it is true that medical treatment decisions for defective infants must often be made very quickly. However, the judiciary can respond quickly in emergency situations, for example, in the case of infants born to Jehovah's Witnesses, often all that is required is a phone call and a transfusion is ordered. Similarly, as seen in the "Baby Doe" case, an emergency hearing was convened in the hospital the evening following the infant's birth.

(2) Frohock's -incrementalist versus final decisionmaking

Frohock describes the ongoing medical treatment of an infant which he explains is always subject to revision and change as the infant's condition changes. However, the courts are not asked nor do they wish to review or supervise the treatment process itself. The courts only become involved when clarification is sought or there is a conflict between the parties involved as to whether treatment may be lawfully withdrawn or should continue. Furthermore, if a court orders that treatment may be withdrawn and an infant's condition dramatically changes, it is open to the physician or parent to obtain an interim injunction, in order to permit treatment to continue pending an appeal. Thus, Frohock's remarks imply a finality to judicial decisionmaking that is not necessarily true.

(3) Dr. Havard's - adversarial v. cooperative approach

Dr. Havard may have been correct that the Director of Public Prosecutions failed to adquately investigate the "medical" facts prior to laying charges against Dr. Arthur, in the Arthur case. However, his remarks condemning the legal systems "adversarial" approach bespeak a basic misunderstanding of the goals of legal decisionmaking. Dr. Havard is equating the process of determining legal guilt or innocence with the quest for scientific knowledge. In a trial, whether civil or criminal, the parties have different goals, while doctors who are making treatment decisions have the same goal - to help the patient. In the latter case, obviously cooperation is essential, while in the former, an adversarial approach allows both parties interests to be protected.

For ongoing treatment decisions which are "medical" decisions a cooperative approach is necessary and beneficial for the patient, but for the ethical/legal question of whether life-saving medical treatment should be withdrawn, an adversarial approach which fully considers all of the arguments in favor and against each position cannot be said to 'harm' the patient nor preclude reaching the truth.

C. Internal Administrative Review

Internal review involves a review of patient care and treatment decisions by doctors and the hospital itself to ensure that consistent high-quality medical care is being provided by each hospital department.

These programs of self-monitoring and review are known as quality assurance programs and have become an important aspect of hospital administration. The goals of such programs are to: (1) identify problems, (2) assess problems, (3) develop solutions to the problems, (4) evaluate the solutions, and (5) monitor the effectiveness of such changes.[89]

In Alberta, the Hospital's Act[90] requires hospitals and their medical staff to monitor patient care. Section 29 of the Act provides:

> The medical staff of an approved hospital
>
> (a) is responsible to the board of the hospital for the clinical and scientific work of the hospital and for advising the board on all matters relating to patient care;
>
> (b) is responsible to the board for reviewing professional practices of the medical staff and other members of the treatment than at the hospital;
>
> (c) is responsible to the board for the improvement of the care of patients in the hospital;

Section 31(2) of the Act further provides that the medical staff or the board of a hospital may appoint a "hospital medical staff review committee" whose function is

> (a) to evaluate and control clinical practice at the hospital on a continuing basis for the purpose of maintaining and improving the safety and quality of patient care, or
>
> (b) to perform any functions in relation to the appraisal and control of quality care in the hospital.

Physician conduct and discipline are governed by the medical staff by-laws which must be approved by the hospital board and require the written approval of the Minister.[91] The legislation also establishes a Hospital Privileges Appeal Board in order to review the decisions made by the medical staff or the Board which pertain to or affect the privileges of members of the medical staff. The Appeal Board is composed of two physicians; a lawyer or a judge; a hospital board member; a nurse and two other persons.[92] A decision of the Appeal Board may be appealed "on a matter of law only" to a Court of Queen's Bench within thirty days of the Appeal Board's order.[93]

Although provincial legislation requires hospitals to institute quality control programs, Magnet and Kluge concluded from their research in 29 Canadian neonatal units that there is a "lack of will to enforce standards in neonatology."[94] A typical example they cite, is the failure to effectively discipline the "loner" specialist who routinely fails to consult with his or her colleagues although this is standard practice in neonatal medicine. Magnet and Kluge contend that the existence of a policy of consultation along with peer pressure is often not enough to ensure that a maverick doctor will comply.

Therefore, they submit that hospitals' medical staff by-laws should be amended to[95]

> require that the Medical Advisory Committee and the Chief of Neonatology give close consideration to a doctor's record of non-compliance with departmental rules and criteria when considering applications for additional or continuing privileges.

They also argue that the Chief of Neonatology should be "given more precise authority and responsibility to supervise the practice of neonatal care, and to ensure that the rules of the Department are served."[96] He or she should be required to discuss the breach of criteria or departmental rules with any offending physician and a written record of such discussions made.

Finally, they submit that a quality assurance process of review should be implemented to ensure that measures to enforce compliance with departmental rules and policies are taken. They suggest that the Minister of Health should appoint a "Quality Assurance Coordinator," whose function would be to investigate and make sure that enforcement processes are being carried out by the Chief Neonatologist and the Medical Advisory Committee.

In the case of the physician who refuses to comply with neonatal policies of consultation, the Coordinator would first ascertain from the Chief of Neonatology and the Medical Advisory Committee (MAC) whether the failure to consult was medically justified in a particular case. If he was unable to obtain assurances in this respect from the Chief or the (MAC), the Coordinator would be required to report the offending doctor's behavior to the hospital board and in extreme cases to the Provincial College of Physicians and Surgeons as well.

Magnet and Kluge suggest that this process of independent review leaves doctors in control of medical decisionmaking and permits self-regulation but at the same time can assure society: "that in exchange for the privilege of self-regulation, they are discharging their responsibility for self-discipline and enforcement." 97

A variation of this proposal is currently in place at the Foothills Hospital in Calgary. At the Foothills, both the MAC and the Patient Care Committee are responsible for monitoring the quality of patient care being given at the Foothills Hospital.

> The medical staff by-laws provide that:
>
> 70.3 The Medical Staff shall establish a Medical Advisory Committee through which all recommendations of the Medical Staff will be channelled. This committee shall be responsible for satisfying itself and in turn, the Board that the quality of medical care in the hospital is continuously being evaluated and shall advise the Board regularly of steps being

taken or which should be taken to perpetuate excellence of care.

70.4 The Patient Care Committee will assist each department to review, analyze and evaluate the quality of patient care given in the Foothills Hospital in its broadest sense and make recommendations to the Medical Advisory Commiteee for the maintenance of this care at the highest possible level. The committee may require from each department any information or report which is pertinent to the quality of patient care.

Each hospital department appoints a member to the Patient Care Committee which must meet on a monthly basis. The Committee's specific duties and functions are: 98

(a) To review, analyze and evaluate the quality assurance program of each clinical department.

(b) To receive periodic reports of the quality of patient care in each clinical department.

(c) To commission individual studies of common diagnoses or operations, to assure the Medical Advisory Committee and the Board that the standard of care at the hospital remains at the highest possible level.

(d) To develop education programs where deficits in the quality of patient care are shown to exist.

(e) To ensure that a regular tissue and death review is performed within the appropriate departments.

(f) To establish such committees

> as are necessary to discharge the duties of the Committee.

Finally, the by-laws require: [99]

> The director of each department shall be responsible for the supervision of the quality of care given by all categories of medical staff within his department for all patients along with the quality of educational programs and research activities of his department. He shall recommend the policies and procedures required for efficient functioning of his department and shall arrange departmental meetings with staff participation therein. He shall see that there is adequate review, analysis and evaluation of the clinical work done in his department ... He shall ensure the appointment of physicians of high calibre and competence to ensure the continuing efficiency of the department ...

The Patient Care Review Committee performs the same investigatory role as a Quality Care Coordinator with two advantages: (1) There is a greater likelihood that abhorrent practices will be identified by medical doctors, than by a non-medically trained Quality Care Coordinator, and (2) offending doctors will be more likely to change unacceptable practices and behaviors if they are condemned by a committee of their own "peers." Furthermore, the Committee's independence is assured since it is composed of members from every department within the hospital.

D. Hospital Ethics Committees

Another method of reviewing treatment decisions made within hospitals is by hospital ethics committees. A predominance of contemporary opinion favours their use although there is as yet no unanimity regarding their roles or composition.[100]

Use of an ethics committee as a review mechanism was first mandated by the Quinlan court. Karen's father and her attending physicians were required to consult with an "Ethics Committee" before treatment could be withdrawn from Karen. The court held:[101]

> If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present condition to a cognitive, sapient state, the present life-support system may be withdrawn...

The Committee the court envisaged, was to be composed of physicians, social workers, attorneys and theologians.[102] Several commentators criticized this aspect of the court's decision, noting that a committee largely composed of laymen would be singularly unequipped to determine what was essentially a medical prognosis question.[103] Since the only function of the committee was to determine if there was a "reasonable possibility" of Karen's regaining cognition, it was suggested that it should be composed of medical experts, particularly those with neurological expertise.[104]

This type of ethics committee is called a "prognosis committee" and the purpose of such committees is to reject or confirm the attending physician's diagnosis that a patient is terminal with no possibility of recovery in order that life saving treatment may be withdrawn.[105]

Robert Veatch, a professor of medical ethics at Georgetown University's Kennedy Institute of Ethics, opposes the use of ethics committees composed solely of medical personnel. He argues that there are three very serious problems with medical prognosis committees:[106]

> First, if there is any merit in the ad hoc, permissive decision making by the individual physician, it is that the physician may know the patient personally, may be committed to giving personal attention ... The committee mechanism bureacratizes death, destroying the one possible advantage of individual decision making.
>
> Second, while the committee may reduce random biases of individual physicians, it in no way eliminates the systematic biases of the medical community as a whole.
>
> Third, even if both the random and systematic bias were eliminated, the

> committee approach would still depend upon and reinforce the misconception that physicians as a group have expertise in making moral decisions about when, if ever, treatment should be omitted or stopped.

Magnet and Kluge also oppose the use of prognosis committees to review treatment decisions in neonatal medicine since they contend that the central issues in neonatal cases, "are often developmental potential and quality of life, not reversibility of coma and inevitability of death" as is generally the rule in the cases where prognosis committees have been utilized. [107] They submit that, "[n]eonatal cases transcend the expertise offered by a committee of doctors." [108]

The composition of an "infant bioethical review committee" endorsed by the American Academy of Pediatrics (AAP), the National Association of Childrens' Hospitals and Related Institutions, the Association of American Medical Colleges, the Federation of American Hospitals, the American Hospital Association and the National Perinatal Association consists of eight members: (1) a practicing physician (e.g., a pediatrician, a neonatologist or a pediatric surgeon), (2) a hospital administrator, (3) an ethicist or a member of the clergy, (4) a representative of the legal profession, (5) a representative of a disability group, developmental disability expert or parent of a disabled child, (6) a lay community member, (7) a member of the facility's organized medical staff, and (8) a practicing nurse. 109 The proposal also provides that individuals who are directly concerned with a particular case (hospital personnel and patient families) would be informed of the existence and functions of the committee and its availability on a 24 hour basis and would be invited to discuss their concerns and add their views to the committee process.

John Robertson has suggested that multidisciplinary committees can perform five major functions. The first, is to provide a forum for identifying, analyzing and resolving the ethical issues involved in serious neonatal cases. The committee attempts to assist the decisonmakers improve the ethical quality of their decisions. A second function closely related to the first, is to educate health care professionals about the non-medical views and dilemmas (i.e., moral and legal) which arise in such cases and possible methods of resolving them. In addition, the committee would also assist in developing hospital policies and guidelines in medio-legal areas (i.e., informed consent, do-not-resuscitate orders). The third function would be to provide support for the families, doctors, nurses and other hospital personnel. A fourth function is to resolve any disputes which may occur among the various parties, such as among the staff, between the staff and physicians, between physicians and parents and among the physicians. Allowing grievances to be aired, explanations given and committee input can reduce misunderstandings and feelings of bitterness which can occur under the stressful situations the participants find themselves in. A final function suggested by Robertson, is that such committees can reduce the risk of all the parties (family, health care professionals and the hospital) from potential criminal and civil liability.[110]

In performing the above functions, there are three major "tasks" the committee should do. The first, is to prospectively review all nontreatment decisions whenever there is some uncertainty as to whether a nontreatment decision is ethically justifiable.[111] Whenever possible an attempt should be made to sustain an infant's life so that a review may be undertaken. Of course, in some cases, decisions will have to be made quickly with no opportunity for prior review. In these cases, the committee may be able to establish some prospective policy guidelines (i.e., resuscitate all infants above 750 grams) as well as retrospectively reviewing the decisions made. The President's Commission stressed the importance of retrospective review of these decisions:[112]

> Ensuring a retrospective review removes any incentive for hasty actions to avoid prospective review, a course that could be a disadvantage at least to some newborns. Retrospective review cannot change what happened to a particular child, but it can help ensure a high standard of decisionmaking practices in the institution and can censure seriously erroneous decisionmaking, both internally and by referral to the courts.

This second task of retrospective review can improve the ethical quality of decisions by openly discussing how decisions could have been improved and suggesting possibilities for future handling of similar cases.[113]

By making it mandatory that medical personnel advise the committee of problematic cases and requiring a retrospective review of such decisions, parents' roles in making decisions for their infants will be enhanced. Physicians are more likely to provide parents with more complete information than they otherwise might, since the committee may be involved. Parents can be given information about the moral, legal and ethical issues involved in their decision as well as being able to express their fears and concerns.[114]

Finally, the ethics committee as it gains experience in handling difficult cases can help formulate a set of guidelines for neonatal decisionmaking within the hospital. Over a period of time standard treatment/nontreatment policies for certain categories or kinds of cases will be settled. For example, there has been an emerging consensus in the past few years that Down's Syndrome infants with otherwise correctable surgical blockages should not be denied surgery because of their retardation.[115] Ten years ago there was greater uncertainty and more debate within the literature about such cases.

Requiring review of difficult treatment decisions by hospital ethics committees is much less cumbersome than requiring all decisions to be reviewed by the courts yet retains the beneficial features inherent in a judicial review as philosopher, Allan Buchanan points out:[116]

> Such a committee would approximate the ideal of the rule of law ... Knowing that decisions reached within this framework are subject to review and further investigation, and that the committee provides a forum for rational discussion, would encourage the family and its advisors to articulate and examine their principles, to strive for consistency and to support their judgments with reasons.

Moreover, the consultative approach taken by hospital ethics committees is less damaging to the actors involved than the adversarial nature of judicial proceedings. In addition, hospital ethics committees can generally act more quickly than the courts as well as avoiding the publicity that is invariably associated with this kind of case.[117] Another practical benefit of committee review which has been suggested is that:[118]

> Unlike turning to the courts for scrutiny of every case involving treatment of a seriously ill newborn, review of this limited category of cases would not seem likely to generate inappropriate social or financial costs.

In a few rare cases, judicial review may still be necessary. Where the committee believes there is a moral obligation to treat or that treatment is medically indicated and the parents refuse their consent, a judicial review is necessary to settle the issue and the committee should refer such cases for judicial determination.

Although hospital ethics committees have clear advantages over other systems of review they are not a perfect solution. Those who have reservations about the use of such committees cite problems such as: difficulty obtaining access to committees;[119] that they are slow to act;[120] they can lead to different hospitals having different treatment policies;[121] committees can be biased;[122] they are not available when needed at 2:00 a.m.;[123] they are impractical and expensive;[124] there is no assurance that their decisions will be consistent,[125] and, that such committees are relatively remote from the emotional aspects of the cases and therefore are insulated from the consequences of their decisions.[126]

Most of these criticisms apply equally well to the courts or any other formal review mechanism that could be devised. However, many of these difficulties could be overcome and no doubt will as such committees gain greater currency. More study is needed about the composition and roles of committees as well as analyzing their successes and failures before a final determination is made regarding their efficacy as a neonatal review mechanism.[127] On the whole, particularly when used in conjunction with an internal system of review and policy setting of the type envisaged by Magnet and Kluge or the Foothills Hospital, they offer the best possibility at the present time for safeguarding against hasty or improperly considered decisions as well as providing needed support for the doctors, nurses and parents who must struggle with the complex medical and ethical issues involved in making these decisions.

6

IV. Conclusion

The complex issues that arise upon the birth of seriously ill and defective infants are subject to varying interpretations depending on whether the analysis is from a medical, moral, legal or policy perspective. At present, the only certainty in the debate over the selective nontreatment of seriously ill and handicapped infants is that the debate will continue. This is true not only because new technologies eliminate some problems while raising new ones but because there is no societal consensus about the value of infant human life with severe physical and/or mental impairments.

From a medical perspective, the inability to distinguish between infants with good and poor prognoses is the most critical problem since the absence of any clear prognosis removes the central core of the medical decisionmaking process.

Many factors are considered in evaluating infants' chances for success and treatment decisions are continuously made in response to changes in infants' conditions. As a result, the choice in medicine is not simply whether to withhold or provide treatment, but rather, what levels of treatment and/or treatment alternatives should be given. Medical writers generally agree that neonatal treatment decisions should be made on an individual, case-by-case basis. The reasons are because of the variety and complexity of cases, and because of the wide range of therapies and treatments which exist (and which are constantly changing). However, there is no unanimity of medical opinion as to the criteria or conditions which would justify a decision to withhold treatment, nor is there agreement as to who should bear primary responsibility for making these decisions. Thus, in some cases, physicians exert pressure on parents to reach the decision the physicians wish, while in others, physicians leave the choice to the parents. Consequently, infants with the same or similar conditions may receive different treatment depending on the particular neonatologist or neonatal unit that is providing their care. Furthermore, since there are no set procedures governing the making and review of these decisions there is no assurance that the decisions are made in accordance with the infants' best interests.

Legal analysis in the debate over the selective nontreatment of seriously ill and handicapped infants has focused on the questions: (1) Who has the right to make these decisions? and (2) What criteria may the decisionmaker consider in making a decision? In answer to the first question, the law generally accords parents the right to make medical decisions for their infant children and requires physicians to disclose to parents adequate information in order for them to make an informed decision. Physicians who disagree with parental decisions may not apply pressure to change these decisions or override the decisions unless they have obtained an alternative valid consent. Legal mechanisms for substituted consent are provided by child welfare statutes and through the courts' inherent _parens patriae_ jurisdiction.

The law imposes a duty upon parents and medical caregivers to provide infants under their charge with the necessities of life which has been held to include medical treatment. Failure to do so on the part of parents or physicians may lead to criminal prosecution and/or civil liability. However, the law permits therapeutically useless or futile treatment to be withdrawn from terminally ill infants with no criminal sanctions attached.

The primary legal criterion in making medical treatment/nontreatment decisions for infants is the best interests of the child. Parental decisions regarding medical treatment for their children will not be interfered with unless their decision(s) is not in their infant's best interests. An analysis of the existing caselaw reveals that parental decisions to withhold or withdraw medical treatment for their seriously ill and defective infants have been upheld by the Courts in the following circumstances: (1) Where the infant is permanently comatose (Re P.V.W.); (2) Where the infant will face a life of irremedial pain (Re B., approved of in Re S.D.); (3) Where the treatment itself is extremely painful and can offer little hope of success (Coutre-Jacquet, Re L.D.K.), but, if the proposed treatment is likely to be successful it would probably be ordered despite serious side-effects (Custody of a Minor - Chad Green case); (4) Where the parents have chosen a medically recognized alternative treatment, which is available (Re Wintersgill); and (5) Where the parent has made an informed and carefully considered decision that is not unreasonable or contrary to the child's best interests (Coutre-Jacquet). However, where parents refuse their consent to treatment merely because the child will have a "poor quality of life" the courts will generally order treatment, (Re B, Re SD) although there has been the rare exception (Becker case).

The enactment of the Canadian Charter of Rights and Freedoms has added a new dimension to the legal debate regarding the selective nontreatment of seriously ill and handicapped infants. Such infants have a right to life (s.7) and the right to equal protection under the law regardless of physical and/or mental disability (s.15). These rights are not absolute however, and therefore must be read along with other provisions in the Charter. For instance, a provincial court judge in the Dawson case held that medical treatment may under certain circumstances constitute cruel and unusual punishment under s.12 of the Charter and the Supreme Court of Canada has recently held in Morgentaler that state enforced medical treatment may be an infringement of an individual's right to security of person (another s.7 right). Thus, there is now a right of privacy recognized in Canadian constitutional law analogous to that found in American constitutional law which would allow a parent or guardian to refuse life-saving medical treatment for an infant in certain cases.

Ethical and moral theories regarding treatment/nontreatment of seriously ill and defective infants range from extreme sanctity of life positions (mandating treatment to preserve life at any cost) to quality of life and personhood theories which would deny treatment or permit the killing of selected infants who do not meet the criteria necessary to achieve "personhood" or a meaningful or acceptable quality of life. Other theorists have suggested that since there is no agreement on the substantive criteria that should guide decisionmakers, the focus should therefore center on devising a fair procedure for decisionmaking and that any decision which is made by following a fair procedure will be considered morally correct.

These theories suffer from a variety of deficiencies. Sanctity of life approaches may lead to overtreatment with aggressive and inhumane therapies being provided where there is no reasonable hope of success. Quality of life theories fail to provide any clear or consistent guidelines to decisionmakers since there is disagreement both as to the criteria and the degree of impairment which preclude an acceptable quality of life. Personhood theories ignore established medical, moral and legal traditions while procedural approaches could result in a wide array of treatment choices for infants with the same or similar conditions, provided a fair decisionmaking procedure was utilized.

On the other hand, the "best interests of the child" approach with its emphasis on balancing the potential benefit or harm to the infant, protects infants from overtreatment as well as undertreatment. A further advantage of this approach is that it is consistent with traditional norms in medicine and law.

Ethical arguments in favour of euthanasia for ill and defective infants fail for both moral and practical reasons. First, although in certain instances killing and letting die are morally equivalent, where death is foreseen but is not intended there is a moral distinction which the law does and should continue to recognize. Second, proposals for legalizing euthanasia ignore the moral costs to the persons who would do the killing and to society for permitting it since it contradicts societal values which purport to protect and uphold innocent human life. As one commentator has warned, there is an emotional difference between killing and allowing a patient to die, and "we can only ignore our deep intuitions at our peril." [128] Third, if euthanasia is morally right for seriously ill and defective infants, it is morally wrong (unjust) not to kill others who suffer from the same debilitating conditions and handicaps. Thus permitting euthanasia for one group should (and probably would) lead to euthanasia for other groups as well and would lead to a societal erosion of respect for human life. Finally, it is not at all clear that euthanasia is necessary. Modern medical advances in pain management can ensure that the vast majority of patients (adults and infants alike) do not suffer from unremitting pain which is the most common reason cited by those who advocate legalizing euthanasia.

It is submitted by the writer (and others) that decisionmaking in neonatal medicine would be enhanced by the development of guidelines or criteria which would specify the conditions in which medical treatment would normally be withheld and those in which it would normally be given. These guidelines would be fairly easy to develop for the most and least serious cases, but would not answer the question of what to do in uncertain cases. Clearly articulated guidelines would however serve to reduce the range of uncertainty and would benefit all of the parties involved. Infants would be less likely to suffer from inappropriate undertreatment as well as overtreatment and there would be greater consistency in decisionmaking. Parents would benefit because these policies would remove some of the burden from their shoulders in making these decisions since they would less likely feel guilty when their choices follow expressly recognized criteria. Physicians would also benefit since the guidelines would minimize the legal uncertainty which currently exists regarding the withdrawal of treatment. Moreover, it would be easier for physicians to discuss with parents treatment/nontreatment options which are in accord with clear treatment policies.

It would be preferable to have input from a wide variety of disciplines in developing these guidelines, (i.e., medicine, nursing, social work, psychology, philosophy, theology, law) as well as parents. It has been suggested by one legal commentator that the Law Reform Commission of Canada would be well suited to hear submissions and develop guidelines in this area,[129], or alternatively, the Canadian Medical Association could be charged with this responsibility.

Individual hospitals would ensure medical compliance with these guidelines through their own quality assurance programs such as the one in operation at the Foothils Hospital. Input from hospitals as well as periodic review of the criteria or guidelines would keep them up to date with current medical developments.

For those cases which are uncertain, the decisionmaker(s) must try to assess the probable harms and benefits of proposed therapies and then exercise his/her discretion in making the decision. To ensure that this decision has been carefully made considering the infants best interests, a mechanism for reviewing these decisions should be adopted. It is submitted that a multidisciplinary hospital ethics committee would be the most appropriate forum to review such decisions. Physicians and parents should be required to meet and discuss with the committee, the issues and factors which influenced their recommendation/decision(s) both in uncertain cases as well as in cases where physicians and parents disagree.

Where a case is uncertain, i.e., the committee itself cannot come to an agreement, the parents decision should be respected. In cases of disagreement between parents and physicians, discussion of the case with the committee would likely resolve the disagreement in most cases. However, where a parent or physician strongly disagreed with the committee's recommendation or where there was strong disagreement among committee members, it would be necessary to seek a judicial determination.

A policy requiring mandatory committee review of difficult neonatal cases would ensure the likelihood that the "best interests" of the infant would be considered by physicians and parents. By making the committee's recommendations optional rather than mandatory, parental autonomy is respected as well as the ethical integrity of the medical profession.

It is recognized that these proposals are not a perfect solution to the complex and troubling issues which arise in neonatal medicine. However, they would ensure that the smallest and most helpless members of our community are accorded the justice (both substantive and procedural) that is the right of every member of our society.

CHAPTER 5 ENDNOTES

1. John D. Arras, "Ethical Principles for the Care of Imperiled Newborns: Toward an Ethic of Ambiguity," in Which Babies Shall Live?, eds. Thomas A. Murray and Arthur L. Caplan (Clifton, N.J.: Humana Press, 1985), p.86.

2. Fred Frohock, Special Care: Medical Decisions at the Beginning of Life (Chicago: University of Chicago Press, 1986), p.25.

3. Id., at 25-26.

4. Robert Weir, Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine (New York and Oxford: Oxford University Press, 1984), pp. 225-27.

5. See Chapter Three, p.p. 284-285.

6. Joseph Goldstein, "Medical Care for the Child at Risk: On State Supervision of Parental Autonomy," (1977) 86 Yale L J, 648. Both the Judicial Council of the American Medical Association and the President's Commission express the view that parents should make treatment decisions, in consultation with the child's physicians, and the President's Commission adds that this should be especially true in borderline cases.

7. A.M. Capron, "Legal Considerations Affecting Clinical Pharmocological Studies in Children," (1972) 21 Clin Research, 141 at 146. Quote is reprinted in President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research. Deciding to Forego Life-Sustaining Treatment (Washington, D.C.: U.S. Government Printing Office, March, 1983), f.n. 70 at p.214.

8. Supra n.4 at 255-56. See also, Leonard J. Weber, Who Shall Live? (New York: Paulist Press, 1976), p.p. 105-06.

9. Paul and Marlys Bridge, "The Brief Life and Death of Christopher Bridge," (1981) 11 Hastings Cent Rep, 19.

10. Norman Fost, "Counselling Families Who Have a Child with a Severe Congenital Anomaly," (1981) 67 Pediatr, 321; Joan E. Hodgman, "Withholding Treatment From Seriously Ill Newborns: A Neonatologist's View," in Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, eds. A. Edward Doudera and J. Douglas Peters (Ann Arbor, Michigan: AUPHA PRESS, 1982), 242.

11. Raymond S. Duff and A.G.M. Cambell, "Moral and Ethical Dilemmas in the Special-Care Nursery," (1973) 289 New Eng J Med, 843. A similar view is expressed by Anthony Shaw in "The Ethics of Proxy Consent," in Decision Making and the Defective Newborn, ed. Chester A. Swinyard (Springfield, Ill. Charles C. Thomas, 1977), p.595.

12. Raymond S. Duff, "Counselling Families and Deciding Care of Severely Defective Children: A Way of Coping with 'Medical Vietnam'," (1981) 67 Pediatr, 316.

13. Carson Strong, "The Neonatologist's Duty to Patient and Parent," (1984) 14 Hastings Cent Rep, 12; Allen Buchanan, "Medical Paternalism," (1977-78) 7 Phil & Pub Affairs, 386.

14. Supra n.4 at 257.

15. Strong, supra n.13 at 10.

16. J.M. Freeman, "To Treat or Not to Treat Ethical Dilemmas of Treating an Infant with a Myelomengocele," (1973) 20 Clin Neurosurg, 141. See Chapter One, supra.

17. Graham W. Chance, "The Severely Handicapped Newborn: A Physician's Perspective," (1980) 2 Health Law Can, 35; Peter Paul Rickham, "The Ethics of Surgery on Newborn Infants," (1969) 8 Clin Pediatr, 252.

18. Shaw, supra n.11 at 594.

19. Supra n.4 at 262.

20. Id., at 262. Medical surveys show that physicians are often willing to accede to parental demands. See for example, I. David

Todres, et al, "Pediatrician's Attitudes Affecting Decision-Making in Defective Newborns," (1977) 60 *Pediatr*, 199.

21. Law Reform Commission, *Euthanasia, Aiding Suicide and Cessation of Treatment*, Protection of Life Series, Working Paper 28 (Ottawa: Minister of Supply and Services, 1982), p.63.

22. Robert M. Veatch, "The Technical Criteria Fallacy," (1977) 7 *Hastings Cent Rep*, 16.

23. Norman Fost, "Ethical Issues in the Treatment of Critically Ill Newborns," (1981) 10 *Pediatr Ann*, 21. See also, Eugene F. Diamond, "The Deformed Child's Right to Life," in *Death, Dying and Euthanasia*, eds. Dennis J. Horan and David Mall (Washington, D.C.: University Publication of America', Inc., 1977), 139. Diamond suggests that infants in NICU's need advocates besides doctors and their parents since such decisionmaking teams have demonstrated a willingness and even a propensity to decide for starvation.

24. J.A. Robertson and Norman Fost, "Passive Euthanasia of Defective Newborn Infants: Legal Considerations," (1986) 88 *J Pediatr*, 888.

25. Id., at 888.

26. Charles C. Baron, "Assuring 'Detached but Passionate Investigation and Decision': The Role of Guardians Ad-Litem in Saikewicz-type Cases," (1978) 4 *Am J L & Med*, 111. Reprinted in *Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients*, eds. A. Edward Doudera and J. Douglas Peters (Ann Arbor, Michigan: AUPHA PRESS, 1982), p.114.

27. Charles C. Baron, "Medical Paternalism & the Rule of Law: A Reply to Dr. Relman," (1979) 4 *Am J L & Med*, 349.

28. Id., at 350.

29. *Supra* n.1 at 86.

30. Hospitals Act, R.S.A. 1980, c.H-11, s.s.28, 32.

31. Public Hospitals Act, S.O. 1981, c.25, s.1 enacting ss. 7(a)(b).

32. Joseph Eliot Magnet and Eike-Henner W. Kluge, Withholding Treatment from Defective Newborn Children (Cowansville, Quebec: Brown Legal Publications Inc., 1985), p.243.

33. Id., at 243.

34. See John E. Pless, "The Story of Baby Doe," Letter to the Editor (Sept. 15, 1983) 309 New Eng J Med, 664; Norman Fost, "Putting Hospitals on Notice," (1982) Hastings Cent Rep, 7; The following discussion of this case has been taken from: Helga Kuhse and Peter Singer, Should the Baby Live? The Problem of Handicapped Infants (Oxford: Oxford University Press, 1985), p.p. 11-17; Rasa Gustatis and Ernle W.D. Young, A Time to be Born, A Time to Die (Reading, Mass.: Addison-Wesley, 1986), p.p. 185-86; Robert F. Weir, Selective Non-Treatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine (New York and Oxford: Oxford University Press, 1984), p.p. 128-29.

35. The presence or absence of other defects is uncertain because the records were sealed in the case. However, David W. Meyers in his book, Medico-Legal Implications of Death and Dying, December 1987, Cumulative Supplement (Rochester, New York: The Lawyer's Co-Operative Publishing Co.), p.196 points out that the Indiana Chief Justice "was reported to have said that Baby Doe died because of insurmountable medical problems, that the child needed extensive surgery and that the existence of Down's Syndrome was only a fact not a factor in the case."

36. In re Infant Doe, No. GU 8204-004A (Monroe County Cir Ct, April 12, 1982).

37. State ex rel. Infant Doe v. Baker, No. 482 S 140 (May 27, 1982).

38. Infant Doe v. Bloomington Hospital, 464 US 961, 78 L Ed 2d 337, 104 S Ct. 394 (1983).

39. 29 USCS ss. 794, 47 Fed Reg 26027 (June 16, 1982).

40. 48 Fed Reg 9630.

41. American Academy of Pediatrics v. Heckler, 561 F Supp 395 (1983).

42. Id., at 399.

43. Id., at 399-400. Affidavit testimony submitted to the Court during the litigation described the operation of these procedures and the adverse effects the procedures had on two hospitals - Strong Memorial Hospital in Rochester, New York, and the other at Vanderbilt University Hospital in Nashville. In each case the investigation disclosed no evidence that handicapped infants were not being given proper treatment. However, the investigations adversely affected the care given by the hospitals. Infants' treatment was delayed due to records being taken by the investigators, doctors and nurses' time was diverted from providing patient care to answering the investigator's questions and parents of infants within these hospitals were concerned and questioned the kind of care their children were being given. These incidents were described by Dr. James E. Strain, President of the American Academy of Pediatrics in a Special Report, entitled, "The American Academy of Pediatrics Comments on the 'Baby Doe II' Regulations," (1983) 309 New Eng J Med, 443.

44. Id., at 400.

45. Id., at 400.

46. 48 Fed Reg 30846-52. For a discussion of the revised rules see: Marcia Angell, "Handicapped Children: Baby Doe and Uncle Sam," (1983) 309 New Eng J Med, 659; George J. Annas, "Baby Doe Redux: Doctors as Child Abusers," (1983) 13 Hastings Cent Rep, 26; Robert F. Weir, "The Government and the Selected Nontreatment of Handicapped Infants," (1983) 309 New Eng J Med, 661.

47. 48 Fed Reg 30852.

48. Weber v. Stony Brook Hospital (NY Supreme Court, October 21, 1982).

49. Weber v. Stony Brook Hospital, 95 App Div 2d 587, 589, 467 NYS 2d 685, 687.

50. Weber v. Stony Brook Hospital, 60 NY 2d 208, 211-213, 456 NE 2d 1186, 1187-1188; cert denied (US) 78 L Ed 2d 732, 104 S Ct 560 (1983).

51. United States v. University Hospital, State University of N.Y. at Stony Brook, 575 F Supp 607 (1983 EDNY).

52. Id., at 614.

53. United States v. University Hospital, State University of N.Y. at Stony Brook, 729 F 2d 144, 150 (1984, CA2 NY).

54. Id., at 156.

55. Id., at 157.

56. Id., at 157.

57. 49 Fed Reg 1622.

58. American Hospital Association et al v. Margaret Heckler, Secretary, Department of Health and Human Services; and Margaret Heckler, Secretary of Health and Human Services, 585 F Supp 541 (1984).

59. Bowen v. American Hospital Association, 90 L Ed 2d 584, 585, 106 S Ct (1986 U.S.). Note: Dr. Otis Bowen replaced Margaret Heckler as Secretary of HHS. See also, Ben W. Heineman, Jr. and Jack R. Bierig, "The Baby Doe Case: Supreme Court Skepticism that Congress Impliedly Authorized a Direct Federeal Role in Areas of Health Care Historically Regulated by the States," (1987) 1 The Health Lawyer, 9.

60. Amendments to Child Abuse Prevention and Treatment Act, Pub L No. 98-457, 98 Stat, 1749 (1984).

61. 45 CFR ss. 1340.

62. 45 CFR ss. 1340.15(b)(3)(ii). See Meyers, supra n.35 at 212.

63. Fed Reg, supra at 14892.

64. Heineman and Bierig, supra n.58 at 12.

65. President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (Washington, D.C.: U.S. Government Printing Office, 1983), p.226.

66. Robert F. Weir, "Selective Nontreatment One Year Later: Reflections and a Response," (1985) 20 Soc Sci & Med, 1112.

67. Joseph E. Magnet and Eike-Henner Kluge, Withholding Treatment From Defective Newborn Children (Brown Legal Publications, Inc.: Cowansville, Quebec), p.p. 248-51; Robert Weir, Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine (New York and Oxford: Oxford University Press, 1984), p.p. 137-39.

68. Magnet and Kluge, supra n.67 at 251.

69. Bowen v. American Hospital Association, 90 L Ed 2d 584, 602 (1986 US).

70. Supra n.65 at 209, f.n.51.

71. Id., at 209 and 215.

72. Supra n.1 at 97-98.

73. Id., at 99.

74. T.S. Ellis, "Letting Defective Babies Die: Who Decides?" (1982) 7 Am J L Med, 417; John Havard, "Legislation Is Likely To Create More Difficulties Than It Resolves," (1983) 9 J Med Ethics, 20.

75. Supra n.65 at 227; Richard Sherlock, Preserving Life (Chicago: Loyola University Press, 1987), p.113.

76. Satz v. Perlmutter, 379 So 2d 359, 360 (Fla 1980). A Similar view was expressed by the

Supreme Judicial Court in Superintendent of Belchertown State School et al v. Joseph Saikewicz, 370 NE 2d 417, 432, f.n. 18.

77. Ellis, supra n.74 at 417.

78. Larry Gostin, "A Moment in Human Development Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates," (1985) 2 Am J L Med, 48.

79. Id., at 48.

80. Id., at 49. See Baron, supra n.26, at 136-37, f.n. 64.

81. E.S. MacMillan, "Birth-Defective Infants: A Standard for Non-Treatment Decisions," (1978) 30 Stan L Rev, 631.

82. Testimony of Dr. Marianne Prout, transcript of the 10th meeting of the President's Commission (June 4, 1981) at 35-36. Appearing in President's Commission report, supra n.65 at 225, f.n.94.

83. Eichner v. Dillon, 73 AD 2d 431, 426 NYS 2d 517 (1980), modified, 52 NY 2d 363, 420 NE 2d 64a, 438 NYS 2d 266 (1981); see also In re Storar, 52 NY 2d 363, 420 NE 2d 64, 438 NYS 2d 266 (1981); In Re Conroy, 98 NJ 321, 486 A 2d 1209 (1985).

84. Saikewicz, supra n.76.

85. Fred M. Frohock, Special Care: Medical Decisions at the Beginning of Life (Chicago: University of Chicago Press, 1986), p.p. 123-24.

86. Id., at 124.

87. John Havard, "Legislation is Likely to Create More Difficulties Than it Resolves," 1983) 9 J Med Ethics, 18.

88. Id., at 18.

89. Supra n.67 at 252.

90. R.S.A. 1980, c.H-11.

91. Id., at s.32.

92. Id., s.33.

93. Id., s.36(3).

94. Supra n.67, at 259.

95. Id., at 260.

96. Id., at 260.

97. Id., at 262.

98. Foothills Hospital Medical Staff By-Laws, s.70.4.03.

99. Id., s.50.2.05.

100. See for example: Allen Buchanan, "Medical Paternalism or Legal Imperialism: Not the Only Alternative for Handling Saikewicz-Type Cases," (1979-80) 5 Am J L & Med, 97; Norman L. Cantor, "Quinlan, Privacy and the Handling of Incompetent Dying Patients," 30 Rutgers L Rev, 243; Alanm R. Fleischman and Thomas H. Murray, "Ethics Committees for Infants Doe?" 13 Hastings Cent Rep, 5; Norman Fost, "Ethical Issues in the Treatment of Critcally Ill Newborns," (1981) 10 Pediatr Ann, 16; Kenneth Kipnis and Gailynn M. Williamson, "Non-Treatment Decisions for Severely Compromised Newborns," (1984) 95 Ethics, 90; Arthur F. Kohrman, "Selective Nontreatment of Handicapped Newborns: A Critical Essay," (1985) 20 Soc Sci & Med, 1091; John A. Robertson, "Ethics Committees in Hospitals: Alternative Structures and Responsibilities," (1984) 10 Qual Rev Bull, 6; Cynthia Taft, "Baby Doe Decisons: A Hospital Manager's Perspective," (1981) 12 Health Care Manage Rev, 61; Robert M. Veatch, "The Technical Criteria Fallacy," (1977) 7 Hastings Cen Rep, 15; Robert F. Weir, supra n.66 at 1109.

101. Matter of Quinlan, 70 NJ 10, 355 A 2d 647, 5672 (1976).

102. Id., at 672.

103. George J. Annas, "In re Quinlan: Legal Comfort for Doctors," (1976) Hastings Cent Rep, 29; H.R

Beresford, "The Quinlan Decision Problems and Legislative Alternatives," (1977) 2 Ann Neurol, 74; Harold Hirsch and Richard Donovan, "The Right to Die: Medico-Legal Implications of In Re Quinlan," (1977) 30 Rutgers L Rev, 267.

104. Beresford, supra n.103 at 77.

105. See Eichner v. Dillon, 426 NYS 2d 517, 549-50 (App. Div. 1980); Matter of Colyer, 660 P 2d 738, 749. See also Arnold S. Relman, "The Saikewicz Decision: A Med[illegible]al Viewpoint," (1978) 4 Am J L & Med, 233.

106. Robert Veatch, Death, Dying and the Biological Revolution (New Haven: Yale University Press, 1976), p.174; Veatch's third argument is shared by Norman Cantor, supra n.100 at 255.

107. Supra n.67 at 265.

108. Id. at 265.

109. The AAP proposal is reprinted in Fleischman and Murray, supra n.100 at 6.

110. Robertson, supra n.100 at 7-8. Similar functions are suggested by Judith Randal, "Are Ethics Committees Alive and Well?" (1982) 13 Hastings Cent Rep, 10.

111. Fleischman and Murray, supra n.100 at 8.

112. Supra n.65 at 228, f.n.99.

113. Id., at 8. See also Buchanan, supra n.100 at 112.

114. Stuart J. Youngner et al., "Patient's Attitudes Toward Hospital Ethics Committees," (1984) 12 Law Med & Health Care, 25. See also Paul and Marlys Bridge, "The Brief Life and Death of Christopher Bridge," (1981) 11 Hastings Cent Rep, 17, who express the fears and concerns parents have in this situation.

115. Graham W. Chance, "The Severely Handicapped Newborn: A Physician's Perspective," (1980) 2 Health Law Can, 36; A.G.M. Cambell, "Which Infants Should Not Receive Interim Care?" (1982) 57 Arch Dis Childh, 569; Raymond S. Duff and

A.G.M. Cambell, "Moral and Ethical Dilemmas in the Special Care Nursery," (1973) 289 New Eng J Med, 890.

116. Buchanan, supra n.100 at 113.

117. Judith Randal, "Are Ethics Committees Alive and Well?" (1982) 12 Hastings Cent Rep, 12; President's Commission, supra n.65 at 227.

118. Supra n.65 at 228.

119. Susan Allen, "No Code Orders vs. Resuscitation: The Decision to Withhold Life-Prolonging Treatment From the Terminally Ill," (1979) 26 Wayne L Rev, 169.

120. Id., at 169.

121. Supra n.85 at 136.

122. Supra n.12 at 317-18.

123. Randal, supra n.117 at 12.

124. Supra n.67 at 268. Magnet and Kluge suggest that this problem could be overcome by a "pooling of resources on a regional basis."

125. Id., at 268.

126. Supra n.4 at 266.

127. Very few studies have been done thusfar on hospital ethics committees, but see: Stuart J. Youngner et al., supra n.114 at 21. Youngner found that patients in one large university hospital believed that such committees were a good idea providing they only gave advice and did not attempt to make the decisions; Cynthia B. Cohen, "Interdisciplinary Consultation on the Care of the Critically Ill and Dying: The Role of One Hospital Ethics Committee," (1982) 10 Critical Care Med, 776.

128. Margaret Somerville in "Are M.D.'s Ever Justified Killing Defective Infants With Lethal Drugs?" by Sarah Scott, Montreal Gazette, August 9, 1986, p.A4.

129. Sneidman, B. "The Steven Dawson Case: Whose Decision Is It Anyway?" (1984) 14 Man.L.J., 165 at 167.

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